

AUTUMN 2019

emphasis

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

Pulmonary Hypertension Awareness Week 2019

4TH-10TH NOVEMBER



LET'S GET #TogetherForPH

Plus...

Surrogacy
& me

Pension
credit

Transplant
Games

Fundraising
news

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Welcome

Welcome to the autumn issue of Emphasis, where we're preparing for our fourth annual awareness week.

PH Week 2019 runs from 4th - 10th November and this time, the theme is all about getting together.

The results of our research into the emotional impact of pulmonary hypertension prove that PH can cause loneliness and isolation, and we're determined to change that. Thank you to everyone who responded to the survey; once again, your voices will make a difference.

Turn to the centre pages to discover some of the ways you can support our awareness week and get #TogetherForPH.

In other news, it was a privilege to be chosen to sponsor the British and World Transplant Games over the summer and we met some truly inspirational individuals at the events we supported in both Wales and Newcastle. You'll find an overview of what went on over on page 10.

It's been fantastic to see so many members get involved with this issue of Emphasis. Heather shares

her experiences of using the Breelib nebuliser on page 36; Jane tells us how crafting helps her deal with symptoms on page 49; and on page 12, Lesley shares her extraordinary surrogacy story.

We're also delighted to share more portraits of PH by Erin Lawson, and to bring you news and experiences from members Yasmin, Michelle and Julie. Thank you to everyone who gets involved with this magazine.

Enjoy the issue, and I hope you will join us in putting the spotlight on pulmonary hypertension during our awareness week in November.

Iain Armstrong

Iain Armstrong
Chair of PHA UK
media@phauk.org





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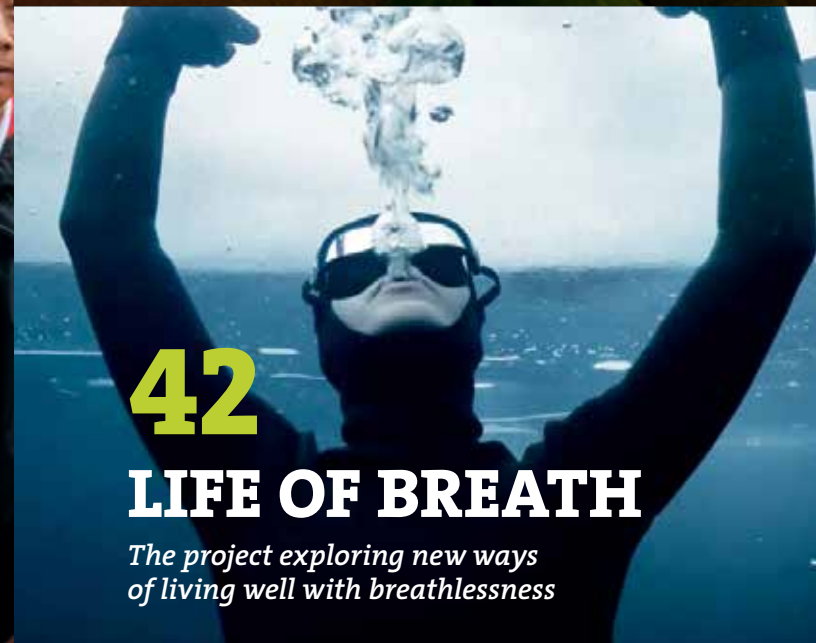
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Emphasis *exchange*

A meaningful Christmas card alternative

If you're looking for a beautiful and meaningful alternative to a Christmas card, these robins made by supporter Lea Acres are just perfect. Lea lost her son Will to PH in 2018 and she is hand-making these porcelain clay decorations to celebrate his life and raise money for the PHA UK. They are available to pre-order from the PHA UK for just £3 including P&P – the same price as a nice card, and your loved ones can hang them on their tree every single year. Please contact us on **01709 761450** or email **office@phauk.org**. They will also be available to order online at **www.phauk.org** soon.

The measurement from tail to beak is 9cm (3.5 inches).



Dear Emphasis,

I thought you might like a photo for the magazine of a fundraising event held for the PHA UK. A lady called Joyce Dickens from Leicestershire organised a Spring Fayre in April. She runs one each year for a different charity, and this year chose ours as she had heard of my illness through friends. My mum and her friends also went along to help run it. They had all of the traditional stalls - including a raffle, name the teddy bear, cake stall and tombola. **But the favourite was the cream teas; they were very popular! In total they raised £1,116 for us. The photo shows Joyce selling raffle tickets.**

Kind regards
Sarah Marshall



Highest-ever organ donor figures recorded in UK

More people than ever are agreeing to donate their organs, according to new figures released by NHS Blood and Transplant (NHSBT).

The increase in the number of donors was made possible partly due to fewer families refusing to support their relative's decision to donate. More families also agreed to support donation, and more people were referred to donation teams by medical professionals.

Anthony Clarkson, director of organ donation and transplantation at NHS Blood and Transplant, said:

"It is testament to the courage of these donors and their families, as well as the dedication of all the clinical staff involved, that we have been able to save and transform so many lives this year."

From Spring 2020, adults in England and Scotland will have to opt-out of having their organs donated when they die. This is in line with the law in Wales, which has meant that 77 per cent of Welsh people now consent to organ donation.

Despite the rise in donations, the number of organ transplants was slightly down, with 87 fewer taking place than the previous year. NHSBT claims the reasons for this are 'still being fully explored by the organ donation and transplantation community'.

NHS
Blood and Transplant

77%
OF WELSH PEOPLE
NOW CONSENT
TO ORGAN
DONATION.

Top Tweets



@Webhelpuk

Well done to the #Webhelp #Rothesay football team for taking part in the Mikey McArthur Memorial Cup this weekend, helping to raise funds for 3 fantastic charities: @AnthonyNolan, @PHA_UK and @brighteststar_1



@lifeofbreath

This powerful film about living with #breathlessness caused by #pulmonaryhypertension by our friends @PHA_UK echoes everything we've heard from our research participants with all kinds of respiratory illness #breathlessnotvoiceless



@capitalbmedia

Great to see a full page feature on @PHA_UK in the new issue of Living North. They work tirelessly to support people living with #pulmonaryhypertension



@Mrawlins1974

Emphasis is a great magazine that tells true and real stories from the heart, offering support and understanding to others.



@carbonscorpion

My wife @mrscharboo has #ph - this is our boy Blue, he's 13 weeks old



@Bewdley_School

Rachel E in Yr 10 will be climbing Snowdon this weekend in aid of @PHA_UK. Rachel was diagnosed with Pulmonary Hypertension in 2015 which completely changed her life. The condition is a very rare and climbing Snowdon will be a huge achievement. Good Luck!



Don't forget we're on Facebook too @PULHAUK



FOLLOW US ON INSTAGRAM!

PHA UK is now on Instagram, spreading the word about PH on another digital platform. Follow us @pha_uk_insta

**CIPR
PRIDE
AWARDS
2019**

GOING FOR GOLD

We're delighted that this magazine has been shortlisted once again in the 'best publication' category at the 2019 Chartered Institute of Public Relations PRide Awards. Emphasis took 'gold' in the category in 2017 and we're crossing our fingers for another win in November. Wish us luck!

"I try to have a positive attitude"

Dear Emphasis,

I am Christine, I am 73 years old and I was diagnosed with Idiopathic Pulmonary Arterial Hypertension in 2007. This was a condition that neither I or my family had heard of before, so it was a shock to learn that it is rare, incurable and life-limiting. I was advised to contact the PHA UK who sent me literature that explained and helped us to understand the condition better.

With the help of family, friends and the medical team I try to have a positive attitude and try to do most of the things I did before my diagnosis but at a slower and longer pace, including some light housework chores, easy gardening, driving, sometimes the school run and looking after our five grandchildren. However, I do know my limitations. I have also taken part in various research and drug trials in the hope that one day, they will find a cure for this condition. My friend Joanna and I are currently organising a patients and carers group at Freeman Hospital, Newcastle where we hold a coffee and cake meeting once a month. New members are always welcome.

Christine Pears

The next patient and carers day at the Freeman Hospital is on 12th October. Contact joannayoungo1@gmail.com for more information.

Hi PHA UK,

I was diagnosed with CTEPH in July 2009. I was already going into right heart failure and was told my prognosis was likely to be five years, maybe less. Luckily, I was fortunate enough to undergo the PTE operation in February 2010 at Papworth, which has enabled me to remain 'stable' all this time.

I thought I'd share these pics of my tattoos I had done to mark the ten-year anniversary of my diagnosis and a celebration of how far I have managed to come.

My first ever tattoos! I was very nervous, but so pleased with how they turned out.

Jenny Jarvis



PAW PATROL

Dear Emphasis,

This is Luna and me, keeping active on a walk through the bluebells last May. I try to walk every day, I always have, but since being diagnosed with PH I make more of a point of it.

It felt a little incomplete going out without a dog. Luna was a stray husky we adopted from our local kennels last November. She doesn't pull on her lead as much as you might imagine and walks at my pace as long as there aren't any distractions (like other dogs or squirrels!). If I get out of breath going up hills and ask her to, she pulls me along!

WENDY CLEMMET



Celebrating LIFE AFTER TRANSPLANT

We were proud to fly the flag for pulmonary hypertension by sponsoring the Westfield Health British Transplant Games and World Transplant Games this summer.

July saw us head across the border to South Wales to support the darts event at the Westfield Health British Transplant Games in Newport.

It was great to catch up with members Dan, Charlie and Katie, along with their families, and to speak to all the athletes and supporters about pulmonary hypertension.

Member Katie Somerfield, who lives just down the road from the darts venue at Rodney Parade, presented the medals to the winners.

Over 1000 transplanted people from around the UK took part in the British Transplant Games.

We made the most of the opportunity by taking branded beer mats, score cards, photo frames and a rather large banner!

“We chose to sponsor the darts because of its unique ability to bring people together in a social capacity. It’s also an accessible sport that doesn’t expend too much energy, so you don’t need to be an athlete to take part.”

SHAUN CLAYTON, DIRECTOR OF MEMBERSHIP SUPPORT, PHA UK



In August we travelled north to sunny Newcastle where we sponsored the Petanque (a game like French boules) at the World Transplant Games.

Around 30,000 athletes from 60 countries took part in a huge range of events across seven days, each one flying the flag for life after transplant.

We were joined by young transplant recipient Charlie Beeton (pictured above with his parents), who helped us present medals to the winners from around the globe, and our associate John Smith represented us in the 5km ‘Donor Run’ for supporters.

Our banners surrounded the Petanque courts, and feather flags stood loud and proud to raise awareness of PH.

“It’s great to see the PHA UK supporting patients on a worldwide footing. It puts the charity right up there in terms of public knowledge and raises the profile of pulmonary hypertension. People are talking about pulmonary hypertension at these games!”

PAUL CORRIS, MEDICAL DIRECTOR, WORLD TRANSPLANT GAMES 2019



FEELING INSPIRED?

Turn to p28 to find out how you can hold your own Darts & Drinks get-together during PH Awareness Week

Whilst celebrating life after transplant during the British and World Transplant Games, we also took time to remember those from our PH community who haven’t been so lucky.

“During these games we’ve seen a real celebration of transplantation, but it’s also important to remember that not everyone is successful while waiting on a transplant list. That’s a sad reality, and it’s one of the reasons we got involved in the games; to help raise the profile of transplantation in the UK. It’s also an opportunity to think of those people that we do know who have been through transplant, particularly with PH, who haven’t had successful outcomes. I wanted us to remember those people during this celebration too.”

IAIN ARMSTRONG, CHAIR, PHA UK

MY SURROGACY STORY

Diagnosed with PH as a baby, 52-year-old Lesley Meek grew up assuming she would never have children – until a promise made at school turned into a son she never imagined. This is her story of starting a family via a surrogate.

I spent the first two years of my life in hospital and, with other health conditions alongside PH, one of my earliest memories is sitting on a small bed with an oxygen tent around me. Growing up was difficult, but I tried not to let it get me down.

At the age of 15 I met my now husband, Byron, and it was around then I was told just how dangerous it would be to get pregnant. None of it came as a shock to me really, and I remember not feeling too bothered about it all.

At a similar time, my dear school friend Valerie and I were chatting between classes and I told her that I would never be able to have a baby.

“Oh, shut up, I’ll have one for you,” was the response.

I never expected it to actually happen!

At that time, I wanted a career; I wasn’t too fussed about becoming a mother. I didn’t want to put my life in danger, or risk the baby having problems - because I knew what that was like.

So, just after my 18th birthday I was sterilised, and a year later Byron and I married. I got a job in a factory via a scheme for disabled people, and life carried on.

KEEPING A PROMISE

Valerie and I stayed in touch and over ten years later, after having two children of her own and going through a divorce, she moved back to Wales from London. I helped her move into her house and she told me that once she had settled in, I could have one year of her life. “Let’s have this baby,” she said. I remember looking at her open-mouthed. Where would we even start?!

The first thing we did was speak to our GP, but they didn’t understand, directing us to a fertility clinic instead. I saw an interview on breakfast TV with the first lady in the UK who had a child through a surrogate, and she spoke about the support she had from an organisation called Childlessness

Overcome Through Surrogacy (COTS).

Back then it was the late nineties and we didn’t have the internet, so my challenge was finding their address. Not knowing where to turn, I wrote to an agony aunt in a magazine, to ask for their advice.

I had a letter back telling me that having a baby via surrogacy would be a bad idea and that it would ruin my marriage. I still have it.

The letter included a leaflet for the National Child Agency, so I rang them, and they put me in touch with COTS.

I received a lot of advice from that organisation, and we discussed it with wider family. We also had many conversations with a solicitor to understand where things stood legally.

“I didn’t feel envious; it was lovely watching everything happen.”

It took about a year from Valerie’s offer to research everything fully and get the ball rolling.

After various medical tests and a lot of support from our local hospital, Valerie became pregnant via artificial insemination, which was successful on the second attempt. It didn’t sink in for a while but when it did, I was very excited. I never worried that she may change her mind about keeping the baby.

I was heavily involved though throughout the pregnancy. I took Valerie to every scan and doctor’s appointment and we spent every day together. I didn’t feel envious; it was lovely watching everything happen.

Most of my friends thought it was great news. My mother

had a couple of question marks over my fitness to look after a small child, but I told her I would take it as it came. I was determined to do the best job I could to look after my baby.

BECOMING A FAMILY

In 1997, my baby Ross was born breach at 8lb 4oz.

My husband and I were both there for the birth and once he was in the world, it was all down to us.

Unfortunately, I lost my mother to a heart attack when Ross was just nine weeks old. It was a case of having to really grow up and get on with it then.

Luckily, Byron and I were – and still are – a strong team. He worked full time in a nursing home while I stayed at home with the baby.

I’m not saying every day was easy; there were hard days, as with any child. But we got along with things fine.

There was no money involved in my arrangement with Valerie. All I did was take out a small insurance policy on her life, which I paid up until Ross was a year old – and that was my decision.

GROWING UP

I did worry about the questions Ross may ask as he got older. We lived in a small village in Wales, where everyone knew everyone’s business, and I didn’t want anyone else to speak to him about it first.

Byron and I received a lot of help from COTS and they guided us through when and how to tell Ross where he came from.

In the end, we did it when he was six and he just accepted it and moved on – it didn’t seem to bother him at all!

“I’m not saying every day was easy; there were hard days, as with any child.”

These days, as a 22-year-old adult, it’s obviously up to him who he tells. He generally chooses to keep it private, and because he looks so much like his father, no-one ever questions him.

We’ve got a great relationship and I’m very proud of him. He recently graduated from university and is just about to start another degree. He keeps in touch with Valerie, and we all get together as friends.

Valerie has never tried to interfere in Ross’s upbringing. She often says that all she did was keep him warm for nine months, simple as that.

Generally, it’s all been a very positive experience for us all, but I know that I’ve been lucky having known Valerie and her family for years.

I went through my surrogacy journey over two decades ago, and I do think it might have been a different experience today. There are so many more constraints now, but there is also a lot less stigma.

My advice to anyone considering using a surrogate is to take your time before making a decision - we spent over a year researching and planning for different scenarios.

I never thought I would be 52 and have a 22-year-old son. I just wanted to live. I had not thought of being a mother, but when it came it was wonderful.



Find out more about Childlessness Overcome Through Surrogacy (COTS) at www.surrogacy.org.uk For information about the legal rights surrounding surrogacy, visit www.gov.uk and search ‘surrogacy’



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unity



The day I met the Queen

When it comes to raising awareness amongst influential people, names don't come much bigger than Her Majesty the Queen. PHA UK member *Yasmin Swift* was able to talk to her personally about pulmonary hypertension and transplants when she opened the new Royal Papworth Hospital in July - and here, she tells us all about it.

It was an honour and a pleasure to be personally invited by Papworth to meet the Queen. It was a secret initially – all I knew is that I would be meeting a VIP – but my mum guessed who it might be and said it was an opportunity not to be missed.

I was chosen to meet her alongside my friend Eliza, who I met when I was having my double lung transplant earlier this year. She was waiting for a heart and the day I was discharged after my operation, she was given the news that a suitable organ had been found.

The team at Papworth said they were so inspired by our friendship and the way we have both embraced our transplants that they wanted us to share our stories with the Queen.

The morning I arrived for the big day, I was told I would also be meeting my surgeon, Pedro Catarino, for the first time. It's weird as I didn't feel nervous about seeing the Queen, but I did about seeing him!

I was advised the Queen had been provided with my history of idiopathic pulmonary hypertension and told that without my transplant, I would have only had two months left to live.

When I met her, she shook my hand and asked if I was able to live life to the full. I told her of my yoga classes, and of the regular walks with my mum. Before she left, I handed her a posy of flowers.

The Queen looked beautiful and wore a stunning pink jacket, hat and pretty dress. She looked younger in person



Yasmin with Pedro Catarino, the surgeon who carried out her transplant

and had the most amazing blue eyes.

I also met the Duchess of Gloucestershire, the Queen's royal correspondents, and her personal cameraman, who was filming our meeting. They were all very friendly and made me feel at ease.

I was told that following our meeting, the Queen remarked how impressed she was by mine and Eliza's bravery and how well we looked.

I had to give lots of media interviews, and it was a long day, but it was a once-in-a-lifetime opportunity that I was very lucky to be a part of.

I felt as honoured meeting the Queen as I did meeting the surgeon who saved my life - as without him and his expertise, I wouldn't be here to tell the story. ●

Are you struggling with stress or anxiety?

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

- Dedicated helpline service 0344 332 9010
- Email support via phauk@anxietyuk.org.uk
- Assessment and therapy provision for those who need emotional support
- Training and resources for PHA UK professionals and members

To find out more about how Anxiety UK can support the emotional aspect of having a diagnosis of PH contact us today on **0344 332 9010**, email us at phauk@anxietyuk.org.uk, or visit www.anxietyuk.org.uk

AnxietyUK

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"I've ticked so many boxes, just by cutting off my hair"

When Michelle O'Hare from Belfast was placed on the transplant waiting list, she decided to go for the chop – raising over £6,500 for the PHA UK in the process. This is her experience of a challenge which sparked conversations about her illness and enabled her to give something back.

I I was diagnosed with pulmonary hypertension out of the blue nearly seven years ago, and in early 2018 I was listed for transplant.

It occurred to me that I was waiting for someone to donate something to me, yet I couldn't even donate blood. That's when I thought about my hair, and how I could give it to the Little Princess Trust to make wigs for children who have lost their own due to illness.

I decided it would also be a good opportunity to raise sponsorship for the PHA UK. It quickly went up into the thousands, and I was amazed.

So many of the donations and messages on my JustGiving page were from friends of friends and friends of family; it wasn't just people from my inner circle. The ripple effect that it had was just amazing.

Initially I was quite private about being ill, until I had to take medical retirement from my job as a teacher. Obviously close friends and family knew there was something wrong with me, but I avoided openly discussing PH because people don't really know much about it.

When I announced I was doing this challenge and started asking for sponsorship, for many people, it was the first time they realised I was ill.

Initially I just sent out private WhatsApp messages, but then I decided to tell people what I was doing on Facebook. Within a few minutes the donations started coming in, from former colleagues, pupils, parents of pupils, and more. Reading about the challenge helped people understand PH and what it means.

It felt great just to get it out there and let people know I was ill. It was my way of saying 'yes I've got this, but I'm getting on with my life'.

Because I look completely normal, people see photographs of me out with friends and think everything is fine, but they don't realise I've had to rest the day before and then spend two days recuperating afterwards, just so I can go out for dinner.

Using the challenge to start conversations was a good way of explaining this to people.

As well as helping children, raising money and generating awareness of PH, the challenge also helped people understand the importance of organ donation. I've ticked so many boxes, just by cutting off my hair.

I felt amazingly calm the day it all came off, which surprised me. My sister came with me and the hairdresser allowed her to make the first cut. She burst into tears because of the significance of it all.

I had 11 inches taken off and my hair is easier to manage now. My PH means I don't have much strength in my arms so just drying it when it was long was a workout. I do plan to grow it out slightly though, so I can tie it back in order to keep it away from my IV line.

I feel a bit guilty sometimes because I did really like my long hair. But whenever I think back to how much money was raised, I can't have regrets. ||

Michelle's fundraising page is still open for donations. Visit justgiving.com/fundraising/michelle-o-hare74

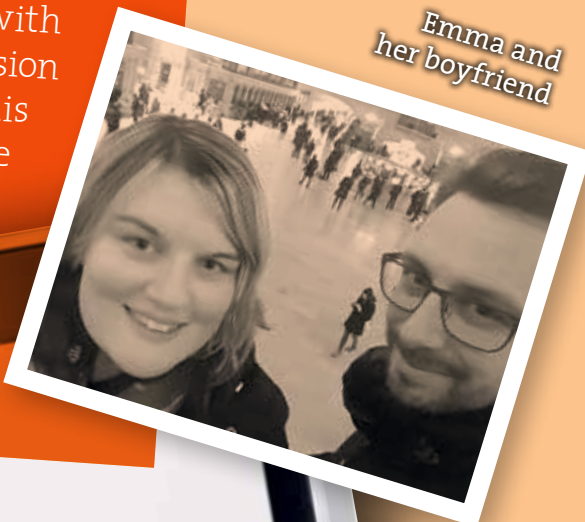
Michelle with her husband

AUTUMN 2019 emphasis 17

Emma Garwood from Brighton was diagnosed with Chronic Thromboembolic Pulmonary Hypertension (CTEPH) following a pulmonary embolism. In this special blog for www.phocusonlifestyle.org, she shares the journey she has been on since.

If you would like to submit a blog for our new website, www.phocusonlifestyle.org, please email media@phauk.org

Emma and her boyfriend



www.phocusonlifestyle.org

"I've realised that life can change in an instant"

I started to become breathless in early 2017. During February to April I visited my doctor's surgery a number of times to try to establish the cause, and they kept putting it down to my asthma flaring up due to the cold weather.

I was given steroids and stronger asthma inhalers, but nothing was working. Before long I became so breathless that I couldn't walk up the stairs in my house without having to stop halfway to get my breath back.

On 11th May I went for a CT scan that revealed a pulmonary embolism in my lungs. I was essentially breathing through a gap the size of a penny, and doctors were amazed that I was actually still alive.

After five days in hospital I was sent home and I am now on blood thinners for the rest of my life to ensure it doesn't happen again. Unfortunately, as the clot was believed to be there for a long time, it has now left me with pulmonary hypertension.

The diagnosis was scary as I'd never heard of getting a blood clot in your lungs before, let alone pulmonary hypertension!

I think the whole thing has really made me realise that life can change in an instant.

After my diagnosis of PH I was told that at some point in my life I might need a pulmonary endarterectomy; which is a super scary prospect to me as it's very high risk surgery and involves a long recovery time.

I think a lot of the struggle comes with not knowing if and/or when I would need this

surgery. Other than that, though, I tend to just get on with things. I'm very thankful that I'm still able to work and lead a fairly normal life; I just get a lot more breathless than other people!

I think my anxiety has heightened since diagnosis.

I think because it took so long to get a diagnosis, I constantly worry that it might come back or get worse and so on.

I get a lot of support from my family, boyfriend and friends which makes it easier to deal with. I'm also in a few social media groups where people who have been diagnosed can discuss various things, so they don't feel alone. It really helps knowing you aren't the only one!

I've learnt a lot about the condition. I never really knew about it beforehand, but I know now that a pulmonary embolism is actually more common than people think. Reading the Emphasis magazine helps to see what support is out there, as well as making you realise that there are other people in your shoes.

I've also learnt a lot about myself; I definitely know that I'm a lot stronger than I thought I was. It's not always going to be easy, but I know that with the right people around me I can get through anything.

My best advice is to go on social media and find a group; talk to people and get an understanding of the fact that it affects everyone differently.

Also, don't be afraid to admit that you need some support or help. It's a really scary time and things are so much easier when you have someone there you can talk to."

Finding a fitness activity *for me*

Catherine Makin from the Ribble Valley has found ballet classes a helpful way of keeping active and building strength. Here, she tells us more.



I was diagnosed with IPAH five years ago. I'm on the transplant list for double lungs and my transplant team and PH centre have always said to try and keep as active as possible. So, I decided to start ballet fitness as a way to keep active and build strength up in my legs and core areas. I have also found something I enjoy doing! I'm not saying I hate exercise, but I don't really enjoy going to the gym or running.

I have been going to the classes since January 2019 and I go with my mum. We both enjoy going and pick each other up if we don't really feel like we want to go!

Classes take place at the dance studios near me once a week and last for 45 minutes. The class begins with us stretching and warming up using the barre and going through the ballet positions eg. first position, second position and so on.

The majority of the class is based on 'traditional ballet'. We then go on to do kicking leg exercises and jumping. We have just learnt a new dance routine which I have tried to join in with, but it gets too much for me as there is a lot of running around involved.

I told the instructor I had PH and she was brilliant; she told me to do what I could manage and if I needed to sit out then that's fine.

During the class I feel relaxed. Sometimes I get breathless with some

of the exercises, for example kicking the legs and jumping, but I just take my time and rest when needed.

When the class has finished, I feel really good about myself. I also feel that I can breathe better and my chest doesn't feel as tight. Sometimes when I have finished work in the afternoon and feel tired, I think 'oh I don't want to go to ballet tonight', but I make myself go!

"Sometimes I get breathless with some of the exercises... but I just take my time and rest when needed"

The class has benefitted me by increasing strength in my legs and core areas, helping me to relax and keeping me fit and active. I feel it has helped my breathing as I don't feel as breathless (although this could also be down to me using the Breelib nebuliser!)

I would advise people who are thinking about taking up exercise to find something you like and take it at your own pace - don't rush into it and rest when needed. Ballet isn't for everyone.





Treated like Royalty

Lifelong Manchester City fan *Julie Royle* fulfilled her dream of watching her team play at Wembley Stadium, thanks to disability tickets. She spoke to Chris Coates about her experience.

PHA UK member Julie Royle has been a Manchester City supporter since 1974. When she was diagnosed with PH in 2012, she didn't think she would be able to attend matches again – firstly due the physical symptoms of PH, but also because of the increased financial pressures that come with the disease.

But in 2016, Julie bought a disabled access season ticket, enabling her to watch the Blues at the Etihad Stadium for the following year.

“The only reason I knew about disabled season tickets at Manchester City was because my son was speaking to one of his friends,” Julie said. *“They aren't well-publicised, but they give people like me the opportunity to do something I didn't think I'd ever be able to do again. To get one, I just had to prove that I receive the higher bracket of Personal Independence Payments due to limited mobility.”*

“It is excellent value for money because not only do I get to see all the home matches, but the ticket also allows entry for a carer as well. My carer does not have to be the same

person every week either – several members of the family have gone with me, so everybody gets the chance to go to the Etihad.”

Last year, Julie renewed her ticket for the 2018/19 season, meaning she was eligible for a disability ticket when Manchester City made it to the FA Cup Final at Wembley in May. She also benefitted from a price cap – disabled seats cost a maximum of £45 in all parts of the ground, less than half the cost of a regular seat in the more expensive areas of Wembley.

“I was hugely impressed with the treatment I received as a disabled person – I felt like royalty,” Julie said. *“We were given a 50 per cent discount for the official car park which was just across the road from the disabled entrance. When we arrived, we were directed into a lift which took us to the first floor, and from there it was a short walk to our seats.”*

“The whole process was painless, and the experience during the game was something I'll never forget, and not just because City won!”

After City blew Watford away with a 6-0 win, Julie said getting out of the ground was just as easy.

“We were sat close to the halfway line and above the dugouts. We waited to let the crowds go, but we were straight back into the lift, across the road and into the car – four hours later we were back home.”

Julie added: *“I thought my chance to watch my team at Wembley had gone, but it shows that you can still get out and do fantastic things with this illness.”*

I feel so fortunate to be able to witness City's most successful season ever, and my experience at Wembley topped it all off. But I wouldn't have done it without my son Alex, who drove me there and back in a day to make it affordable and restful for me. I'm now planning more adventures and I'm going to enjoy them all!” ●



Julie's experience of the Etihad Stadium could be replicated at the team you support, particularly if they play in England's top two divisions. The Premier League introduced new rules in 2015 which require clubs to provide a proportionate number of accessible seats to their total ground capacity, generating an extra 1,000 disabled seats. If you have PH and love your football but struggle with the experience of visiting your home ground as a regular ticketholder, it may be worth contacting your club to see if there is any accessible seating you could take advantage of.



Contraception & pulmonary hypertension

A comprehensive guide to birth control and PH.

Contraception, and the whole issue of pregnancy and PH, has changed a lot over the last 20 years.

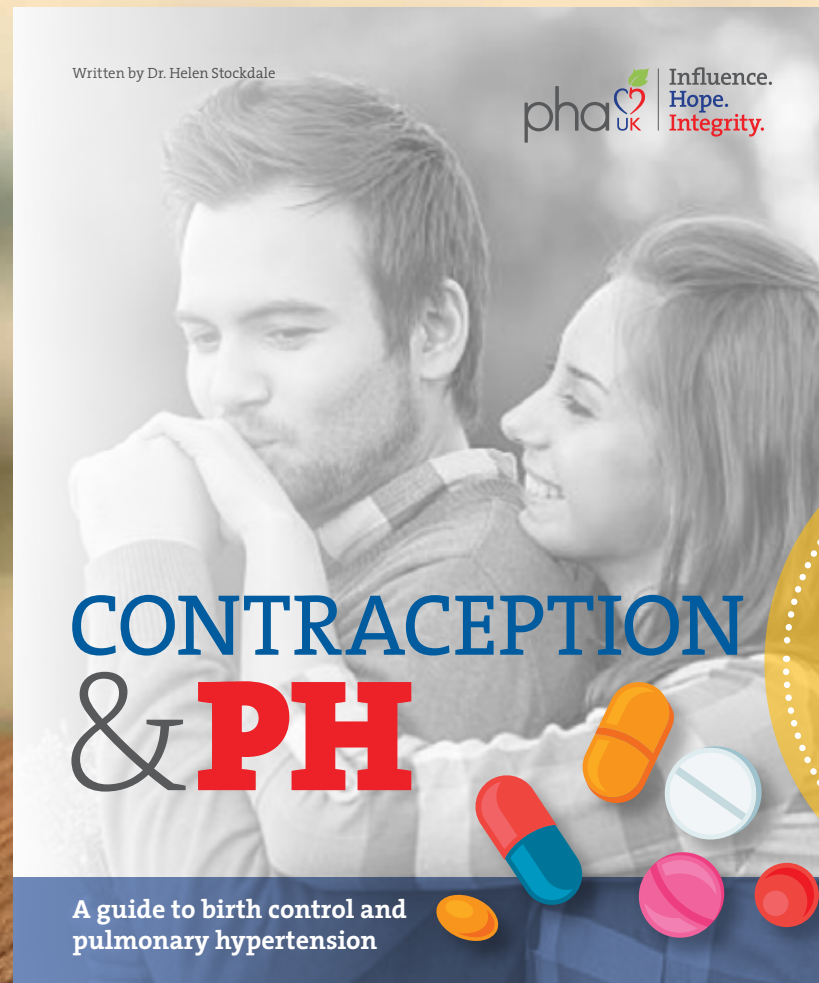
We've worked with experts to produce a guide that brings you the facts about birth control to help you make the decisions that are right for you.

Pre-order your FREE copy...

www.phauk.org
office@phauk.org
01709 761450



This book is supported by a trio of short films offering expert advice around contraception. Visit www.phocusonlifestyle.org to view them online.



Could you benefit from pension credit?

Following the news that people over 75 will have to pay for their own TV licence unless they receive Pension Credit, PHA UK's director of membership support **Shaun Clayton** explains what we know about this under applied for benefit.

What do we know about Pension Credit?

Pension Credit is what's called an income-related benefit that's made up of two parts.

The first is something called Guarantee Credit - this is the part that tops up your weekly income to £167.25 for single people or £255.25 for couples, if your regular state pension falls below either of those figures. It's worth noting though that if your partner is your carer or you're responsible for a child under 20 who is in full-time education, you may be eligible for slightly more.

The second part of Pensions Credit is Savings Credit, which is slightly more individual so unfortunately, I cannot give you facts and figures. What I can say is it's an extra payment for people who saved some money towards their retirement, rather than a pension as such. Again, it's worth noting that you may not be eligible for Savings Credit if you reached State Pension age after 6 April 2016.

How can I claim Pension Credit?

Unfortunately, you can only claim Pension Credit once you have reached the State Pension age of 68 for men and 67 for women. If you are in a couple, one of you must be receiving a form of Housing Benefit in order to be eligible for Pension Credit. You will also lose Pension Credit as a couple if you start living with someone who is below State Pension age. But if you're unsure about whether you're eligible, there is an online calculator on the gov.uk website that looks at your current financial situation and offers an idea on how much support you can expect. If you're happy to do that, why not apply?

We know from our recent Financial Impact Survey that living with PH can cause financial pressures, so we're always looking out for ways to relieve it. There is nothing to lose and the statistics don't lie - Pension Credit is a massively underclaimed support tool.

If you're looking for more information on Pension Credit, visit www.gov.uk/pension-credit



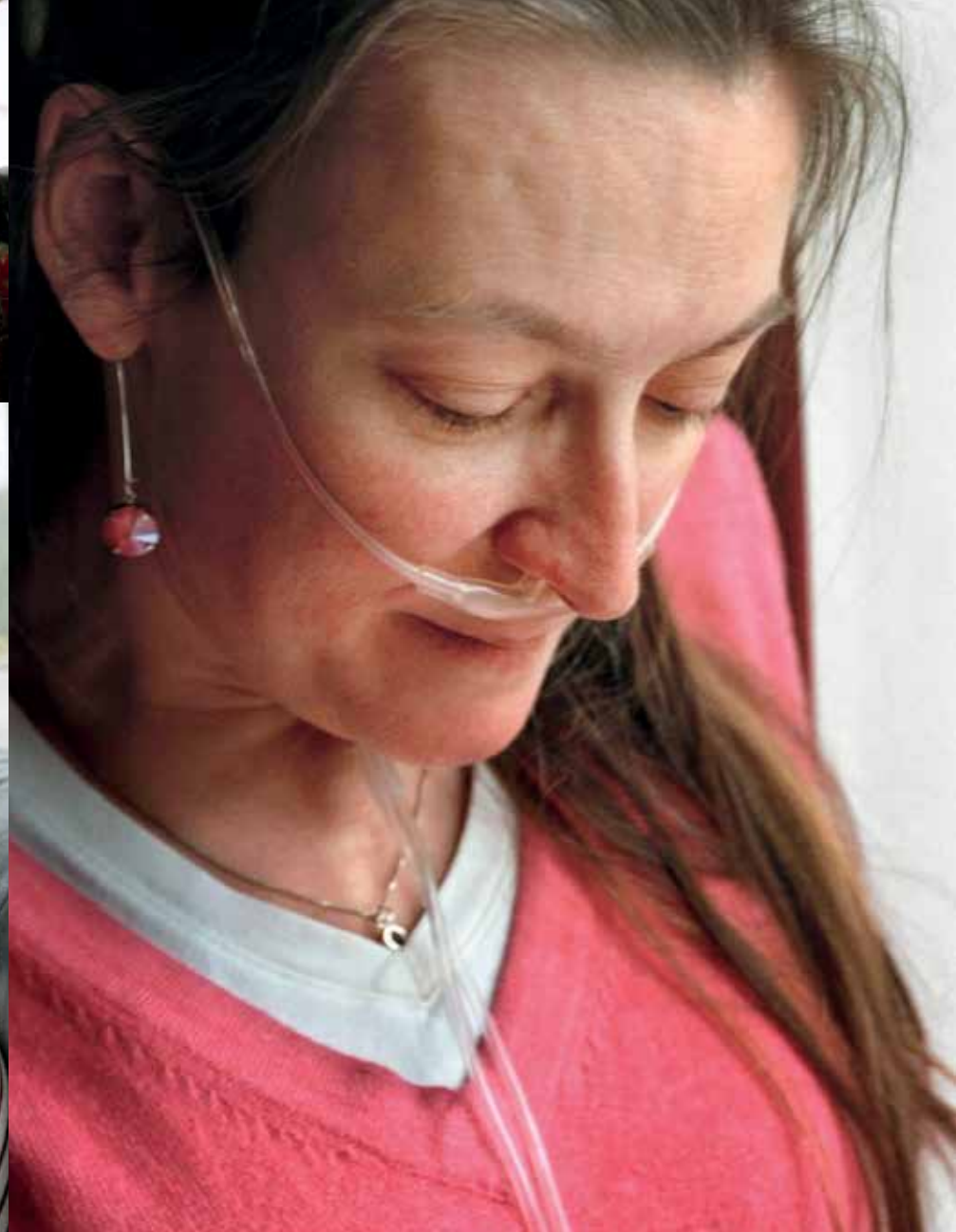
In my experience Pension Credit is an underused resource – a lot of people don't know it's available. If you receive a lower rate of State Pension, you could be eligible without realising.



This is us...

In the spring issue of *Emphasis*, we brought you a special feature showcasing the work of photography student *Erin Lawson*. She was so inspired by her mother Carolyn's journey with PH that she decided to make it the subject of her university project by capturing the family's experiences – resulting in some really special images. Since then, Erin has met more people living with pulmonary hypertension in the UK and photographed them at their homes.

Here are just some of those portraits of PH.





Do I need to exercise to lose weight?

Shaun Clayton, nutritionist and director of membership support at the PHA UK, offers his advice around a very common question.

We've included a few features about the benefits of physical activity and exercise in recent issues of *Emphasis*, so I felt that it was important to tackle this subject here. Lots of people think 'to lose weight I must exercise'. This is something that has moved from being a myth to now being perceived to be a law in weight loss. It's not true, and I'm about to explain why...

I should probably preface this with some context before I get told off by colleagues! I am not saying that exercise isn't important. It is, and there are psychological and physiological components to exercise that a good diet simply cannot compete with. But when we solely look at losing weight, nutrition here is king.

We've all heard the phrase 'it's 80 per cent diet and 20 per cent exercise' and I'd argue that for diet, that number isn't high enough.

In the last issue of *Emphasis*, I explored the laws of energy balance and explained how you have a certain

amount of energy coming in versus a certain amount of energy going out.

'In' comprises what you eat and drink, whilst 'out' is made up of three components – **the daily functions of simply being alive** (breathing, eating and so on); **daily activity such as walking around the house**, climbing the stairs or going to the shops; and **more structured physical activity** such as swimming, cycling or walking.

For weight loss, what if I told you that the 'in' is much more important than the out? Focus on consuming the appropriate number of calories for your goals and any exercise is the icing on top of the weight loss cake (probably not the best analogy here, but hey!)

So, let's say that exercise is simply not an option for you. Remembering that exercise is just one part of the three-part 'out' component, that's fine, and here's why:

- One hour of weight training = around 180 calories which is equivalent to a Cadbury Crème Egg

- 45 minutes of non-stop swimming = 450 calories which is two chocolate ring doughnuts
- Two hours on the bicycle (less than 10km/h) = 960 calories which is a large Big Mac Meal*

So, when you consider that if you were just to cut these things out of your diet, then for weight loss you'd be in the same place as if you had done that exercise.

You might be thinking 'yeah that's great Shaun but how do I know what's appropriate for me'? Let's start with addressing the dietary 'low hanging fruit': How many sugars do you put in your tea, could you halve the amount? Could you change that can of Coke for Diet Coke? When you're cooking your meal, do you need all those chips?

You'd be amazed at what simple changes can achieve! ●

If you have a question about nutrition that you would like to see answered in a future issue of *Emphasis*, please email media@phauk.org

* (This data has been adapted from Bouchard et al (1983) and is based on a male weighing 100kg)

LET'S GET TOGETHER FOR PH!

#PHWeek19
#TogetherForPH

PH AWARENESS WEEK

2019

4-10 November

JOIN US!



Turn over to see how you can get involved >>>

Get #TogetherForPH

During the summer we conducted important research into the emotional impact of pulmonary hypertension - and the results show just how isolating this invisible illness can be.

We'll be using PH Week to launch the findings of our survey and encourage

people to get together to enjoy company and raise awareness of PH. This year, we've got two event ideas to help you get together with friends, family or colleagues - and perhaps raise a few pounds for our charity too.



TEA & TALK

A coffee morning at home or work is a great opportunity to bring people together, and it couldn't be simpler. After all, we all love a cuppa and a chat!

Incorporating a bake sale gets more people involved and turns your get-together into an instant fundraiser too. We can provide cake toppers and signs, bunting, posters and information sheets - you just need to supply the cakes!



darts & drinks
FOR PH

DARTS & DRINKS

If pubs are more your thing, this one's for you. Enjoy a pint (or a soft drink of course!) and set up your own darts competition at your local.

We can provide special PHA UK beer mats and darts flights - so you'll be doing your bit to raise awareness amongst the regulars too.

**NEW
FOR 2019!**



GET QUIZZICAL!

Why not incorporate a quiz into your coffee morning or darts event? PHA UK member Rob Owen has kindly provided us with quiz sheets put together by himself, covering topics as diverse as dogs, sport and geography. Email us at media@phauk.org if you'd like a copy.

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Download your **FREE Tea & Talk or Darts & Drinks event packs** at www.phauk.org If you don't have a printer, or would prefer a free pack sending through the post, call us on 01709 761450 or email office@phauk.org. Packs will be available from October.



Spread the word online

Social media is a brilliant way to show your support for PH Week and raise awareness of pulmonary hypertension. Here's how you can get involved:

- Change your profile and cover images. Visit www.phauk.org to download yours from October!
- Share a selfie. Take a photo with the cards we provided with his issue of Emphasis and share them online, remembering to tag us in. To help us make an impact, save your snaps until PH Week 4th - 10th November! You can even get your pets involved too!
- Tell your followers why you're supporting PH Week. Help them understand why raising awareness is so important.

Don't forget to use the hashtags **#PHWeek19** and **#TogetherForPH** on your posts!

We'll be posting lots for you to share on our own social media pages. Make sure you're following us on these platforms:



Post a pledge - and ask your MP too!

Pledge your support for people with PH on our online pledge wall - available live at www.phocus2021.org soon.

This is also a great opportunity to ask your MP to publicly show they care about people living with pulmonary hypertension. Simply fill in a short online form, and your pledge will appear for the world to see. Keep an eye on our website and social media channels for further details.

**NEW
FOR 2019!**

More ways to get involved over the page! >>>

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Share your story

Your local newspaper, radio or TV station will love to hear about your reasons for supporting PH Week, and it's a great way to reach lots of people with your story.

We've got lots of advice on contacting your local media at www.phauk.org.

You can also send your story straight to us, and we can share it as a blog on our online platforms.

Contact media@phauk.org and we'll guide you through the process. Handy with a smartphone? You could even record your own video!



**NEW
FOR 2019!**

LITTLE PHIGHTERS

This year, we'll be dedicating a day during PH Week to raise awareness of pulmonary hypertension in children.

We'll be launching a special new resource designed to help parents and guardians and we can't wait to share it with you. We'd love to put the spotlight on little phighters during PH Week.

Send us a photo of your child and tell us how they inspire you, and we'll share it on our online platforms. Email your pics to media@phauk.org



Want to talk to us about PH Awareness Week? Call 01709 761450 or email media@phauk.org. We'd love to hear what your plans are!

Visit www.phauk.org for more ideas and downloadable resources

emPHasis-10

A game changing quality of life measure

The 20th anniversary of PHA UK is a good time to reflect on one of our biggest achievements - the development of the EmPHasis-10 questionnaire. Chris Coates spoke to healthcare professionals and researchers to find out why the survey has been so successful.

When you go into clinic, you will have been asked to fill in the EmPHasis-10 questionnaire. This short survey measures the impact of PH on your quality of life using just ten questions and filling it in during your treatment also allows clinicians to assess what is working for you.

The questionnaire was first compiled by Iain Armstrong, Chair of the PHA UK, and Janelle Yorke, Professor of Nursing at the University of Manchester. It has now been translated into over 25 languages.

Iain completed a PhD in pulmonary hypertension in 2013, and it was then that the development of EmPHasis-10 began. He said: "I was looking at the place of hope in life threatening illness and was aware at the time that it was actually very difficult for individuals to explain to clinicians about how PH impacts on their quality of life. The tools available were often quite complex and not sensitive enough to look specifically at PH itself."

Iain added: "EmPHasis-10 is what we call a disease-specific quality of life measure, and one that could easily be completed frequently in clinic. It's a tool in which an individual could have a conversation with healthcare professionals and say, 'This is what having PH is like.' I think it's absolutely crucial."

Janelle Yorke says the questionnaire is the 'world leader' for assessing quality of life for PH patients.

"It's being used in nearly all PH clinics across the UK, and nurses in particular have received very good feedback from patients when it is completed before they go into a consultation," she said. "It helps the nurse to facilitate a more person-centred consultation because the conversation can be based around what their scores on the EmPHasis-10 are and what items seem to be bothering them the most."

The success of EmPHasis-10 has led to its use worldwide. Janelle added: "It's been translated into Chinese and Japanese and it's also being used in an audit across the USA for Chronic Thromboembolic Pulmonary Hypertension (CTEPH). So, it's picked up a lot of momentum around the world and is being cited by more and more PH scientists and clinicians as a useful tool."

THE QUESTIONNAIRE IS THE 'WORLD LEADER' FOR ASSESSING QUALITY OF LIFE FOR PH PATIENTS.

According to Janelle, the success of EmPHasis-10 is one of the most significant outcomes of the PHA UK since it was formed in 1999. A study is currently taking place to determine whether it could even be more effective than the World Health Organisation Functional Class as a measurement of life expectancy for people with PH.

"Patients find it very useful – it describes how they're feeling and they like the fact that it's short and simple to use," Janelle added. "Many quality of life questionnaires can have lots of pages to complete so they like the fact that there are only ten items which touch on what's important to them."

Wendy Gin-Sing, Clinical Nurse Specialist in the Pulmonary Hypertension Service at the Hammersmith Hospital, said: "The questionnaire is easy to use and the simple scoring using a scale of 0-5 means that with one glance you can assess a patient's current quality of life. Also, because it is a disease specific quality of life questionnaire, it can identify subtle changes in exercise capacity and energy levels that other measurements may miss."

"Exercise tests and cardiac catheters can give us data about how well the body is functioning but EmPHasis-10 allows us to measure quality of life, which is often the most important factor for our patients as well as the team looking after them."



Czech, Hebrew and Japanese are amongst the many languages in which emPHasis-10 is now available.

Clinical trial set to test the benefits of supervised exercise for PH

A major study to test whether supervised exercise can help people with pulmonary hypertension is now underway in the UK.

The Supervised Pulmonary Hypertension Exercise Rehabilitation (SPHERE) trial is being led by clinical exercise rehabilitation experts and researchers from University Hospitals Coventry and Warwickshire NHS Trust, and the University of Warwick Clinical Trials Unit.

Funded by a £1.3million grant from the National Institute for Health Research (NIHR), the trial aims to find out whether out-patient exercise rehabilitation, combined with motivational support, can improve fitness and quality of life for people living with pulmonary hypertension.

The study is interested in all types of PH, but particularly PH secondary to heart and lung disease.

The study aims to enrol 352 people with pulmonary hypertension who live near one of ten or more rehabilitation centres in the East and West Midlands, and who agree to be randomly allocated to supervised exercise with motivational support, or to continue with 'usual care' (general physical activity advice).

The project will start in Coventry, Birmingham, Leicester and Dudley, but further down the line it is likely that people in other parts of the country can get involved too.

What will the study involve?

The exercise rehabilitation group will be invited to complete eight weeks of twice-weekly supervised

out-patient exercise. An exercise programme has been developed which is suitable for people with all types of pulmonary hypertension and can be delivered within existing NHS exercise rehabilitation services.

Typical activities will include treadmills, exercise bikes and rowing machines, as well as functional fitness exercises using steps, a floor agility ladder, a low-rise balance beam, power bags and ball throws. The idea is to improve strength, agility, co-ordination and balance, as well as reducing breathlessness.

The exercise programme has been tested, evaluated, and refined over a six-month period and the study will be run in specialist rehabilitation centres by staff experienced in treating people with heart and lung conditions.

Participants will be offered support to reduce anxiety and help them stick to the exercise programme.

People in the 'usual care' group will receive general physical activity advice, but not supervised exercise.

Clinical exercise physiologist Gordon McGregor is leading the study. He said: **"From talking to people with pulmonary hypertension, we know that the most important benefit of any treatment is reduced breathlessness and fatigue. People have told us that this would reduce anxiety about daily activities, helping them to 'do more', walk further and have a better quality of life."**

"So, we will use a walking test and quality of life questionnaires



"Supervised exercise rehabilitation is a common treatment for many heart and lung conditions, such as heart attack and COPD. It can improve fitness, breathlessness, anxiety, depression, and overall quality of life."

Clinical exercise physiologist Gordon McGregor

over one year to measure if exercise rehabilitation helps people with pulmonary hypertension and represents good value for the NHS."

The PHA UK is supporting the study by updating members on its progress and ensuring that everything is done in the best interests of people affected by pulmonary hypertension.

Gordon added: **"The PHA UK is the loudest voice in support of people affected by pulmonary hypertension in the UK and we are delighted to be working alongside them for the benefit of the pulmonary hypertension community."** ●



"Pulmonary hypertension has a major impact on quality of life, so we support quality research that seeks to improve this for patients and their loved ones. There is a richness of strong evidence that points to the highly positive impact of regular physical activity. We will be following and supporting the progress of this study closely. We look forward to seeing the results, and the ultimate benefits for people living with pulmonary hypertension."

Iain Armstrong, Chair, PHA UK



For more information, including updates on recruiting participants, please visit www.warwick.ac.uk and search for SPHERE.



Green Leaf Crew!

GREEN LEAF CREW Q&A AALIYAH MITCHELL

Aaliyah Mitchell is ten years old and lives in Rainham, Essex with her mum and little sister Amaya. Aaliyah was diagnosed with PH in 2013. Here she shares some of her favourite things.

Q. What do you like to do at school?

A. I love painting and arts and crafts. I enjoy painting using lots of different colours with my friends and getting really messy.

Q. What's your favourite thing to do at the weekend?

A. I love going shopping for fashionable clothes. I also like painting my nails, going to the park and making slime at home with my sister using lots of different colours.

Q. What's your favourite food?

A. I love Chinese and Japanese food. My favourite place to eat is Wasabi sushi. I love a bit of spice!

Q. What do you like to watch on TV?

A. I love to watch Henry Danger on Nickelodeon.

Q. What would be your dream job when you're older?

A. I would love to be an actress.

Q. Where do you like to go on holiday?

A. My favourite place to visit abroad is Miami in Florida.

Q. If you could be anyone in the world for a day, who would it be?

A. I would like to be Charlotte, an actress from Henry Danger, because she is very funny and makes me laugh.

Q. If you could have any superpower, what would it be?

A. I would like to be able to turn invisible, especially when I have an MRI scan at the hospital.



AALIYAH WITH HER SISTER AMAYA

FORAGING FOR NUTS & BERRIES



At the end of summer, a range of wild nuts and berries start to grow – you just need to go to your nearest woodland to find them. Here are four you can pick and eat!

Blackberries Blackberries are fairly common and grow in woods and hedges. The berries should be a deep purple-black – if they are not, this means they are not ripe and should not be picked. You could use them to make a blackberry pie or an apple and blackberry crumble.

Elderberries Elderberries are easy to find and grow in groups of five on plants with green toothed leaves. These small, dark red-black berries can be added to sweet pies, crumbles or jams.

Wild raspberries Wild raspberries are quite common if you look in the right places. They are smaller than raspberries you buy in the supermarket. You can use them to make a raspberry trifle or cake.

Hazelnuts You can forage for hazelnuts by finding a hazelnut tree and shaking it. The nuts should fall and then you can collect them. But nuts are a squirrel's favourite food, so they might beat you to it! It's best to forage in the autumn because the nuts are ripe and brown, so they taste better.



The GREEN LEAF CREW

BY DAVID BANKS



A HUGE THANK YOU to Charlotte Killick School of Dance and Starlight Kids from Lancashire, whose dance show was featured in the summer issue. We're delighted to say they raised over £1,000 for the PHA UK, in support of young Matthew, pictured, who was diagnosed with PH as a newborn.

My Breelib challenge...

PHA UK member Heather Pollitt (pictured) has recently transitioned onto Breelib, a nebulising device used to take the drug Ventavis. In this special feature for Emphasis, she shares her experiences and advice.

Breelib is the size of a mobile phone and it has a rechargeable battery inside. The specialist nurse asked if I felt that I could try it. It would open up the small arteries and the drug would go straight to where it was needed via the nebuliser, thus avoiding any side effects.

I bowl up at Sheffield Hallamshire complete with overnight bag and a list of all the medication I'm already taking. There's a lovely bed waiting for me in a room with three other women, all of whom have PH and one other person who'd come to be inducted into Breelib.

The learning process started straight away! I was shown how to assemble the electronic nebuliser, which meant clicking two essential parts into place. Then I was shown the small glass phials of Ventavis that looked like dolls' house glass skittles all packed in a row.

I was shown how to use a plastic applicator to break the top off the phial and then how to syphon the liquid from the phial and squeeze it into the heart of the nebuliser. Click the top down and then it's ready for use. Press the button and, hey presto! It lights up!

Now, if you've been a smoker, and I'm a 'never' smoker, you have a decided advantage. It's like an E cigarette. That's why it took me a few goes before I got the knack of it. Pam, the nurse,

demonstrated how to draw the mist into the lungs in a series of slow, steady breaths.

She had a 'dummy' version with water in hers. After about four tries, I got it! It's all about breathing in and not letting any breath go outwards and into the mouthpiece.

It took about three minutes before the device flashed three times to tell me the dose was complete. I felt so stupidly proud of myself! But Pam made me feel as though it was a real achievement.

After each dose, the device must be dismantled and rinsed in zero water, which is filtered water. There's a special filter jug provided with a tiny tap on the base for filling up small bottles.

The whole thing has a neat carrying case for going out with. It's functional but I could think of a nicer colour than the strident turquoise that draws attention to itself! Black or grey would be much better.

The rest of my induction story is quite smooth. I had no ill effects: I was using the device efficiently and all my 'numbers' were ok when I said goodbye to all my new friends and struggled to carry home a cart load of equipment in boxes and bags. The refills and subsequent doses were going to be delivered as required.

I didn't feel any better for about four weeks! And I got fed up and despondent at having to do this procedure every three hours! I couldn't believe how quickly the time went by. Then gradually over the course of one week, I began to feel brighter and to breathe more freely.

Now it felt worth all the trouble. And by now I'd got used to how to cope with taking the dose in a café or in my car. I can honestly say I've not had any strange looks or been questioned as to whether or not I'm smoking. I had all my retorts ready though. 'Have you heard of the incurable invisible illness?' I would say, waving the PH information sheet at them, but this was absolutely not needed.

I guess my biggest triumph was to travel to Spain, taking the Breelib nebuliser into the cabin and using it during the journey. Here's the procedure, which worked fine with Ryanair.

- Apply online for a permission to carry a medical device for use on the flight. (you need a 'fit to fly' signature from your consultant or GP.)
- Complete and return the form by email to the flight operators.
- They will stamp the form and email it back to you. Keep this to show at the airport.
- Just take one or two doses with you into the cabin. Check in the other phials to be put into the hold.
- Just do your procedure then squirt the zero water on to the parts, patting them dry with a tissue. (It's best to do this in your seat to avoid germs in the plane toilet!)

It all worked for me and it can work for you! Stick with it and it could make a big difference, or even a small difference, to your life. Ventavis has a cumulative effect and that's why it takes time to kick in with some people. And that's why we have to take six doses per day to keep the levels up. I wish you well!

These are the questions I asked, and the answers I received, before agreeing to start this new procedure:

- Q. Why do I need to come into hospital?**
- A.** Because we must make sure that you know how to use the nebuliser properly. It's quite complicated. Also, we want to monitor the initial effects of the drug.
- Q. Will I see a consultant?**
- A.** Yes. One of your consultants will be overseeing the process while you're with us.
- Q. Is this a new drug?**
- A.** No. But the nebuliser is new. Up to now there's only been an IV method of administering Ventavis but now there's the nebuliser. They're working on an oral version but it's not ready yet.
- Q. What if it doesn't work or I don't cope with it?**
- A.** Then we take you off it and try something else.

You might wish to have a discussion with a member of your PH specialist team to find out more about nebulised treatment and whether it could be an option for you. It is not a treatment option that is appropriate for everyone.

For more details about nebulised iloprost, please see p17 of '**Medication & PH**', the PHA UK's new guide to treating and managing pulmonary hypertension. Call **01709 761450** or visit **www.phauk.org** to order your free copy.



FUNDRAISING focus

Playing hockey in Joyce's memory

David Winstanley organised a charity ice hockey game in memory of his mum Joyce, who died in 2009. The game took place on what would have been her 62nd birthday. David said: "My mother, in the early stages of her illness which went undiagnosed for a long time, spent her time driving me miles away from home to Deeside Ice Rink so that I could practice and play the game I loved, because nothing made her happier than seeing her children happy. This is my way of paying tribute to all those great parents out there and a special thank you to my late mother Joyce for all her time spent freezing in the rinks over the years and putting in the miles. I'm forever grateful."



Conwy Marathon for Sandra

Paul Hulme completed the Conwy marathon, raising £1,248 in memory of Sandra Teece, who died in 2018. Meryl Teece, Sandra's sister, said: "We all had a fantastic day, although it was very emotional and poignant. We are all so proud of Paul and he has helped to keep Sandra's memory alive. He completed the run in 4hrs 48mins which was an incredible time for him as he has never run a marathon before."



Marathon run for Margaret

Richard Cowell completed the London Marathon to raise money for PHA UK in memory of Margaret Parsons. Richard said: "It was a completely overwhelming experience and very tough going at times. Margaret's husband and son were there to cheer me over the finish line having previously told me they could not make it, so it was a bit emotional to say the least! So far I have raised over £1000 on JustGiving which I am very pleased about."

Coastal challenge for Kirsty

A team of 13 from Nationwide Building Society in Bournemouth walked 37 miles along the Dorset coast to Weymouth, raising over £3,000. One of those who took part was Jessica Bramely, whose sister Kirsty died in 2015 after being diagnosed with PH. Jessica said: "A great effort was put in by everyone and we are all able to hold our heads high with this monstrous challenge we have completed. For people suffering from PH being able to walk down the street can be a challenge, so this trek really brought home to us how lucky we are to be able to do this. We raised a huge amount of money with donations still coming in, and I know that it will go a long way."



Conquering the Mongol rally

Ben Heyman and four of his friends are taking on the challenge of a lifetime to support PHA UK. They're driving 12,000 miles from Sussex to Ulan Ude in Eastern Russia in a 20-year-old, 1-litre Volkswagen Polo. To follow their progress, search 'baby don't yurt me' on Instagram.

Could your employer help your fundraising?

When you're doing your fundraising, why not ask the company you work for to match your donation? James Richards, who cycled across Spain in May for the PHA UK, raised £6,000 after DPD agreed to match the £3,000 he raised from his own fundraising.



ORGANISING A SPONSORED WALK... IN FOUR SIMPLE STEPS

Sponsored walks are one of the most popular ways to fundraise because they are easy to organise and suitable for most ages and abilities. Here's a handy guide to setting one up.

- 1 CHOOSE THE RIGHT DATE**
Consider planning your walk in the summer months which are less likely to be affected by the poor weather. Also, arrange the walk well in advance to avoid clashes with other events.
- 2 THINK CAREFULLY ABOUT YOUR ROUTE**
Pick an interesting, varied route where you start and finish in the same place. You want to get the balance right between walking in quiet picturesque areas and busier places where more people will see what you're up to. Also try to include a pub or cafe which you can stop off at midway through the walk.
- 3 MAKE SURE EVERYONE HAS THE RIGHT EQUIPMENT**
Provide fellow walkers with information on appropriate clothing and footwear. Even if it's the middle of summer, if you're walking on rural footpaths it's still likely to be muddy in places. Ensure everyone has a map of the route and emergency contact numbers in the event of someone getting lost.
- 4 TELL YOUR LOCAL MEDIA**
Get in touch with the local newspapers, online sites and radio stations to advertise your event. You can also carry out your own promotion through social media, emails, posters, and by setting up an online fundraising page.

IF YOU'RE PLANNING A SPONSORED WALK CONTACT office@phauk.org OR 01709 761450 AND WE'LL SEND YOU A HANDY FUNDRAISING PACK TO HELP WITH YOUR EVENT. LET US KNOW HOW YOU GET ON!

HAPPENING
SOON!

We love hearing about your fundraising adventures!
Email media@phauk.org for a chance of seeing yourself on these pages.

STRUGGLING WITH MONEY?

► Find out if you could access welfare benefits, charitable grants and other support that you might be missing out on.

TURN2US.ORG.UK



PHA UK members can also use the Turn2us Benefits Calculator and Grants Search tool via **www.phauk.org**

The lowdown on type 2 diabetes

More people than ever are being diagnosed with type 2 diabetes, but there are things you can do to lessen your risk. Here's what you need to be aware of...

Type 2 diabetes is a serious condition which - if left untreated - can result in long-term health complications. But it's equally important to stress that its development can often be managed with the right care and attention.

What is type 2 diabetes?

In essence, type 2 diabetes is when someone has too much blood sugar, which is also called glucose. When someone doesn't have diabetes, their blood sugar levels are controlled by insulin produced in their pancreas. But if they have type 2 diabetes, the insulin they do produce doesn't work properly or there isn't enough of it. This results in their blood sugar levels becoming too high.

What is type 2 diabetes?

Someone with type 2 diabetes may experience symptoms such as:

- Excessive thirst;
- Needing to urinate more frequently than usual, especially at night;
- Weight loss;
- Blurred vision;
- Cuts or wounds that heal slowly;
- Extreme tiredness;
- Itchiness around the genital area or frequent episodes of thrush.

Who's most at risk of developing type 2 diabetes?

- Those who are overweight or obese;
- Those with close relatives with diabetes - such as parents, brothers or sisters;
- Those who are over 40 - or 25 for south Asian people;
- Those of south Asian, Chinese, African Caribbean or black African origin.

Just how common is type 2 diabetes?

According to Diabetes UK, more than 4.6m people in the UK now live with diabetes.

Around 90 per cent of these have type 2 diabetes, while the remaining 500,000 live with other types of diabetes. Diabetes UK also predicts that more than 5m people in this country will have diabetes by 2025 if nothing changes.

Getting tested - and what happens then...

Make an appointment with your GP if you have any symptoms of diabetes - or if it's prevalent within your family. Your GP will check your urine and also arrange a blood test to assess your glucose levels. If you're subsequently diagnosed with type 2 diabetes, your GP will discuss with you:

- What type 2 diabetes is;
- What high blood sugar means for your health;
- The medicines you'll have to take;
- How frequently you'll need to test your blood sugar levels;
- Your diet and exercise regime.

Preventing the condition

A healthy diet and keeping active will help you manage your blood sugar level. It will also help you to control your weight and generally feel better.

You should eat a wide range of foods - including fruit, vegetables and some starchy foods like pasta - and keep sugar, fat and salt to a minimum.



For further information on type 2 diabetes, visit www.nhs.uk or www.diabetes.org.uk

Living well with Breathlessness

A unique research project is using activities like dance, art and writing to explore new ways of living well with breathlessness.

Mary Ferguson found out more.

Life of Breath is a five-year research project, funded by the Wellcome Trust, to look at new ways of answering questions about breathing and breathlessness and their relationship to illness and wellbeing.

The project is jointly led by Prof. Havi Carel of the University of Bristol and Prof. Jane Macnaughton of Durham University, and the wider team includes researchers from subjects including medicine, philosophy, anthropology, history, arts and literature.

The project also works with people living with lung disease, healthcare professionals, and people who use their breath in interesting ways, like musicians.

Participants have been recruited to activities including dance workshops, art projects, singing groups and even 'movement playgrounds' – where people are encouraged to move in an unchoreographed way.

Durham University-based Dr Sarah McLusky is project manager for Life of Breath. She said: "Breathlessness is about more than just the biology. People can have very good objective lung function measures but feel very compromised, and vice versa. It was obvious, at the start of the project, that

there was so much more going on there."

Sarah said one of the most interesting elements of the project has been seeing how some of the different approaches to working with breathlessness have given people a sense of control over their situation.

"That's something that seems to come up again and again. Whether it's breathing exercises to help them in the moment or writing things out to help them manage their emotions, it all comes down to the notion of giving someone a bit more control - which may have been taken away from them at diagnosis."

One of the key aims of the project, which is now entering its final year, is to develop an approach that promotes 'wellness within illness'.

"We want to show that although illness closes some doors, it can open others too", said Sarah.

"Breathlessness can cause the world to shrink around someone, and their only safe space may be a particular chair or bed - because of that fear."

"So, we're looking at how everything from physical and creative activities to breathing exercises can help support the person going through the process."

The findings from the singing groups

are an example of how this approach can deliver positive results.

Sarah said: "Some of the feedback we get from the singing is that people benefit from being part of a group, the support that comes with that, and the sense of it being a shared experience. They tell us they have a sense of feeling uplifted, that's really hard to quantify, and that's something you'll not be able to get from a lung function test."

Alongside singing, writing and music, the dance workshops are having the added benefit of helping people engage with exercise.

And although the dance classes are currently only being trialled in Darlington and Newcastle-upon-Tyne, Life of Breath is working with partners to enable them to become permanent fixtures, as part of the legacy of the project.

Sarah added: "Ultimately, one of the legacies we want to leave is to campaign for more research to be done - but not just around the biomedical aspects of breathlessness. We need it to centre around the human being who is actually living with that breathlessness too."

Find out more at www.lifeofbreath.org

Catch Your Breath

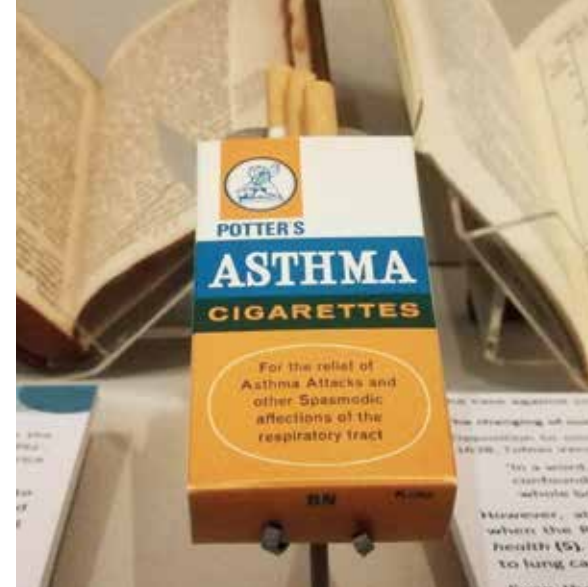
The Life of Breath project has been raising awareness of the impact of breathlessness via a unique exhibition working its way around the country. 'Catch Your Breath' uses objects, visuals, sound, interactive materials and events to tell the story of how our relationship with, and understanding

of, the breath has developed over time. One of the highlights of the exhibition is a specially commissioned film which shows people living with chronic illness explaining how breathlessness affects their lives.

Sarah said: "The inability to 'catch your breath' is commonly used as a metaphor for breathlessness. Not being sure that the next breath will be easy or safe can be a terrifying experience. One of our main aims for this exhibition was

to share the stories of people who live with breathlessness in an attempt to challenge the stigma that surrounds it."

Catch Your Breath has already been on display in Durham and London and is now available to explore in Bristol. You can see the exhibition for free at Southmead Hospital and other venues in Bristol until 27 February 2020. It can also be experienced online at www.catchyourbreath.org

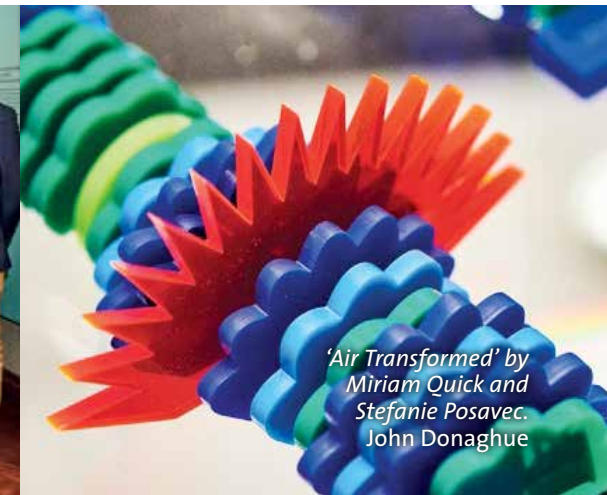


"Breathlessness is a very personal experience... Some people deal with breathlessness better than others. As a result, doctors find it hard to measure and difficult to treat. Those living with breathlessness are often forgotten. We want to help people live well with breathlessness."

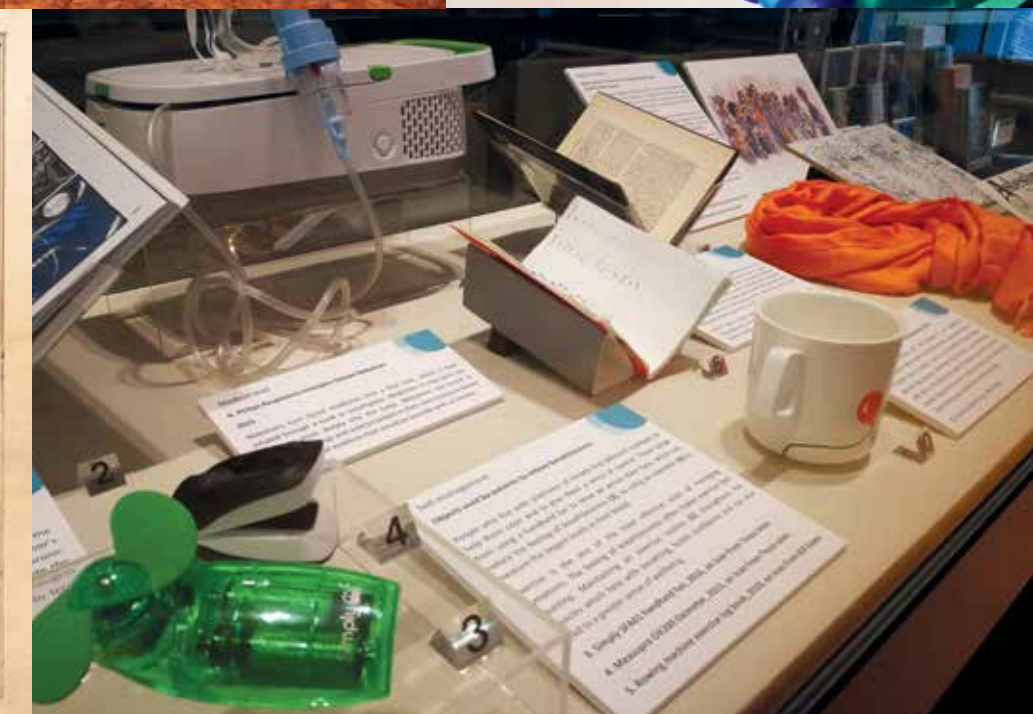
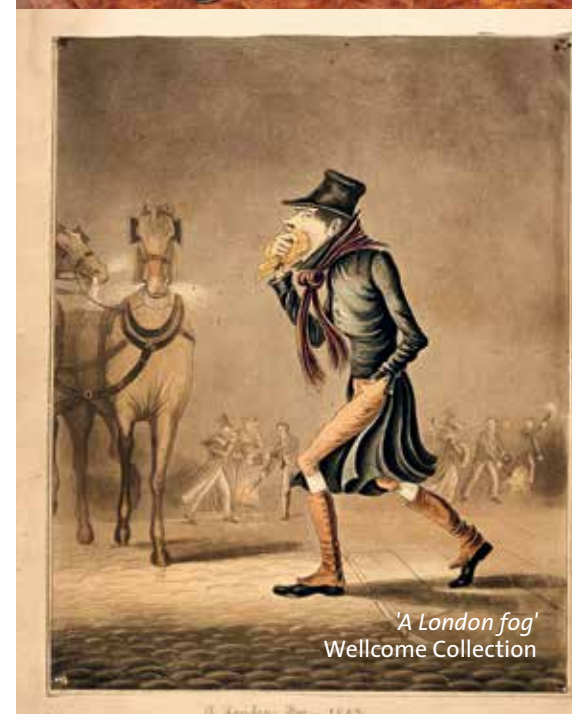
www.lifeofbreath.org



The Life of Breath team - Jane and Havi are in the middle and Sarah is fourth from the right



'Air Transformed' by Miriam Quick and Stefanie Posavec. John Donaghue



Johanna Under the Ice Ian Derry



theinterview



Clinical nurse specialist
at the Royal Brompton Hospital

CARL HARRIES

in conversation with
Chris Coates

Carl Harris is a clinical nurse specialist at the Royal Brompton and Harefield Hospital. He grew up in Llanelli and trained in Cardiff, before moving to London in 1994 to study a degree in cardiac nursing. It was there that Carl found the speciality of congenital heart disease, and within that was the Pulmonary Hypertension Unit.

Carl became a clinical nurse specialist at the Royal Brompton and Harefield Hospital in West London in 2000. When he joined, the service treated around 20 patients, but that has now grown to around 800, of which 600 are under regular therapy.

Carl was involved in establishing the emPHasis-10 questionnaire, which is now widely considered to be one of the best ways

to measure the effect of PH on a person's daily life. He also co-wrote the book 'It Matters To Me' with PHA UK Chair Iain Armstrong, which covers the effect of PH on relationships and intimacy. The book is now used by the American PH Association. He has worked closely with the PHA UK for many years.

Having lived in London for over 20 years, Carl enjoys returning to his hometown of Llanelli to visit family and visiting the picturesque West Wales coastline close by.



Q. As a child, what did you want to do when you grew up?

A. I remember when I was about five years old, I walked into hospital to visit a relative and I remember the distinctive smell hitting me. I loved that smell, and by the age of 14 I just thought 'I want to be a nurse'. I'm not sure where that concept came from, but it was in my head and then I lived the dream.

Q. Did PH find you or did you find PH?

A. My background is in cardiac nursing and I came to London to do a specialist course at the Royal Brompton Hospital. It was there that I found the speciality of congenital heart disease, and a position came within the hospital for a specialist nurse with the emphasis being on congenital heart disease and PH. So PH found me really, and it was the best thing that could have happened because congenital heart disease and PH were my favourite areas anyway.

Q. What engaged you to work around PH?

A. Working with congenital heart disease means you work with the very young to the very old and I liked that aspect. Looking after young people is a niche that some people find very hard, but I found myself very comfortable doing it. For young people with PH you're giving them life-long care so they need continuity and somebody they feel they can trust and that's what I feel I bring.

Q. What are the challenges of living with PH compared to other respiratory diseases?

A. I think the first challenge of PH is actually getting your head around the diagnosis. It's a disease many people have never heard of and it can come as a shock because they don't realise that it's degenerative and progressive if not treated. There's an emotional burden for people with diagnosis and for me it's a case of hopefully getting them through that crisis or hard time in their life.

I also think the fact it's a hidden illness is a challenge because patients have to adapt their lifestyle in lots of ways. In previous years where they've been fit and well, all of a sudden they might not be able to play with their children, for example. The basic day-to-day aspects of their life are usually changed overwhelmingly by the fact of their diagnosis. The classic example is the window-shopping experience of patients where they'll stand and look into shop windows without having any inclination of what they're looking at. All they're concentrating on is getting their breathlessness back on an even keel. But the fact it's a hidden disease means it only usually manifests itself when you're walking down the street and people with PH can't keep up with you.

Q. What is the most rewarding thing about your job?

A. Seeing somebody getting better and coping with their illness, getting on with their life and putting the condition... >>>

“Working with congenital heart disease means you work with the very young to the very old and I liked that aspect.”

...itself on the backburner. There's also something rewarding about seeing patients who have met the challenge and start raising awareness through the PHA UK of how they're actually coping with it. Having the bravery to put themselves out there and being a face of PH makes it real. I've been working as a clinical nurse specialist for over 18 years at the Royal Brompton. We started off with a very small group of only 20 patients in therapy, and that's now grown to about 800 patients of which 600 are in therapy, if not more. My main role is to take a patient through diagnosis and, if appropriate, then treatment, and also help them manage their life with PH. That could be various aspects of living which has nothing to do with the condition itself. It could be work related or family related, it could be dealing with the diagnosis itself.

Q. What achievements are you most proud of?

A. I think one of the biggest things we did as a group of healthcare professionals was develop the emPHasis-10 questionnaire. I think that was a remarkable feat and it includes all types of patients with PH and it's a validated tool in that it works and it measures what it's meant to measure. It's been taken on around the world and it's a British model of assessment – that is something that the PH community should be proud of. I also wrote the 'It Matters To Me' book, along with Iain Armstrong, which is about relationships and intimacy, and that publication has been taken on by the American PHA. That's one of the biggest things for me - seeing that publication not only come about in the UK but also spread its wings to America. One of the things I love about my job is being able to work with a charity and the publications they do, and that's probably the best example of it in terms of my contribution. PH is a remarkable condition like lots of chronic diseases and the impact that it has on people's relationships is still under investigation. From anecdotal experience it can have a huge impact on relationships and the book is designed to bridge a conversation between a couple, or between friends because it's not all about intimacy, but it's about opening up so you can speak to each other. Maybe your relationship will grow and maybe where that's taken a hit, the wounds of PH can heal in terms of the relationship.

Q. What does an average day look like for you?

A. An average day at Brompton is answering the phone and responding to emails which are predominantly patient-focused. I've got two other colleagues and we take it in turn each week to be the nurse on call for the wards for inpatient and day case management of patients, treating patients and diagnosing them. Clinic is also the unique time where you can meet patients to see how they're actually getting on with their lives because it's not a hospital clinical setting in terms of the ward environment. It's usually a time where patients will have had time to think about things they want to discuss with you and in terms of nursing, there's an intimacy of nurse-patient relationship where questions

are asked which can prove to be very difficult or they felt that they couldn't ask the doctor because of the type of setting it's in. My time is also taken up with service development as the lead nurse.

Q. Who inspired you in your work?

A. I think the people that inspired me at the outset of becoming a clinical nurse specialist were the consultants that I've worked with. That would be namely John Wort and Michael Gatsulis at that time because they placed a huge amount of respect and trust in me and it was the level of autonomy that they gave me in those early years which meant it was a steep learning curve. They allowed me to hold the service together and with them we made the service grow. It was one nurse, one consultant and one secretary, but from that to this day we are now five consultants, three nurses, one PH service co-ordinator, one designated PH secretary and a database clerk. The amount of work and awareness that we do within our own service is huge and we have become a speciality within our own right within the organisation. I'm proud of the fact that I've been here from the start and we now have better care for people living with PH – both patients and their carers and families.

Q. How would you describe the work the PHA UK have done since the charity was established?

A. I think what the PHA UK have done is they've reached out to their members and provided patients with a remit to understanding their condition. They're also a platform for patients to find their own means of support, they're dedicated to a rare disease area which I think is huge in that they not only support patients but they also support the development of other services within the national PH Service in terms of the centres that look after these patients. They help with establishing posts – we're hoping that we will get our own dedicated physiotherapist soon. They're a charity that is active and always evolving. The beauty of my job is that I can work with the charity and it's a different level of experience in that it gives the position I've got even more value. The way that they engage health professionals is not superficial – even doing things like this interview is a privilege in that respect.

Q. What do you enjoy doing outside of work?

A. A big part of my life are my friends and doing things with them is important to me, especially living in London away from family. Theatre is one of my favourite things to do. I also like live music – Camden Roundhouse is a favourite haunt of mine. I grew up in Llanelli – that's the other thing I like to do, go back home and visit family. I really love West Wales and the coastline. The one thing about living in London is I do miss the sea – there are amazing coastal pathways and small towns. One of my favourite places to go is a place called Solva. If you drove through and blinked you'd miss it but it's a peaceful and unreserved type of place to be and totally contrasts with London. But I enjoy coming back to London and city life - I've lived in North London for over 20 years. ●

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Reviews

Would you like to review an app or book which may be of interest to Emphasis readers? Please contact media@phauk.org

This issue we review two very different books, which are both powerful in their own ways.

This is going to hurt

By Adam Kay

This non-fiction book is a collection of diary entries written by Adam during his medical training between 2004 and 2010. It's absolutely superb. I never imagined I would find anything other than a novel to be a page-turner, but this was exactly that. I thought about this book a lot and looked forward to going to bed so I could read it. Kay manages to mix heart-breaking memoirs from his time in obstetrics and gynaecology with laugh-out-loud humour and a wit that doesn't get tiresome. He describes in intense detail the horrors of childbirth, which is the only reason I didn't give it a full five out of five. Personally, I found that a little off-putting! This is an important read for anyone with any kind of stake in the NHS – whether you're a patient, an employee, or simply someone who makes National Insurance contributions. It shows the human side of a service that we simply could not live without. Kay is now a comedian, about as far from the NHS as you can get, and after reading this book it's easy to see how he got there. His razor-sharp humour offers light relief from the despair of some of the situations he describes, producing a truly unique book that is very hard to put down. Everyone should read it.

Reviewed by Mary Ferguson

MARKS OUT OF 5?

4.5

Hardcore Self Help: Fk Anxiety**

By Robert Duff

You can't ignore this book. Well, not its front cover anyway. It might not be to everyone's taste, but it provokes a response from the audience it is aimed at; which is basically young men. And that is no bad thing when young men can be the hardest to reach to talk about mental health issues. I'd left it on the coffee table by accident when two male relatives came round (one late 20s, the other early 30s), and they both picked it up and started talking about personal anxiety issues; proof (although not very scientific) that it gets men talking. But is it any good once you get past the front cover? (Interestingly there are no words on the spine, which means you could hide it on the bookshelf.) Well, yes actually. It is very easy to read. The chapters are short, the examples are clear and easy to relate to, and it explains concepts well. It normalises anxiety as an appropriate psychological and physiological response to challenges that can get out of hand, and looks at how to deal with that. There is no psychobabble, but lots of useful exercises and links to websites. I work in a university setting with students and also with young people in private practice, and I will be recommending this book. But be warned: this book is not for everyone, it even says that in bold inside the front cover. However, if you don't mind the expletives and the Americanisation it could be a useful tool for dealing with anxiety.

Reviewed by Elaine Thélér, Counsellor and Outdoor Therapist

MARKS OUT OF 5?

4

CREATE AND ENJOY



Jane getting crafty



PHA UK member Jane Barker-Benfield uses textile arts and crafts to help her cope with life with PH. She wrote this article for Emphasis to inspire others to get crafty too.

my propensity to over-think everything. I try and work on something every day, even for a few minutes. It really helps.

My weekly sewing class has become a lifeline. Sometimes I don't feel up to going but I know once I get there, I feel so much better for it. My teachers and fellow stitchers are so supportive, encouraging and inspirational. I often don't get much sewing done as I'm too busy chatting and having a laugh. Sewing classes should definitely be available on prescription!

Going to a weekly class is great but if you can't get to one regularly there are many one-day courses available, or you can tap into the countless free tutorials and craft communities online.

Textile crafts are something that can be done by everyone and **it's a great hobby if you have limited mobility.** It doesn't matter if you start something and don't finish it. There's as much pleasure in the creative process as the finished project. Every crafter I know has lots of UFOs (unfinished objects) tucked away. My current UFOs are a needle felt rabbit, a goldwork Tudor rose and a crochet blanket.

Unless you're like me and have hordes of fabric, threads and haberdashery squirreled away in every room of the house (including the bathroom), you don't need a lot of space. Depending on your choice of project, it's a very portable hobby. **I take something to work on when I go to clinic appointments or have to stay in hospital. It helps me zone out from the anxiety of tests, procedures and the inevitable, but**

necessary, information overload.

It doesn't have to be expensive either. I get most of my fabrics from charity shops, recycling existing fabrics or donations. **For every technique and ability level there are lots of kits available.** They are often free with craft magazines which can be a good way to start.

Don't worry if things go wrong – they will. I've probably unpicked more stitches than sewn. A snow leopard I recently finished needs corrective surgery to make it look less scary. My first attempt at needle felting – a mini unicorn – morphed into a mouse because I overworked the wool. I've never got on well with dressmaking. My one attempt was a disaster. **The nearest I'll get to the Great British Sewing Bee is having the same colour blue nail varnish as one of the presenters. Create and enjoy!** ●



Pictured: some of Jane's crafty creations.

Medicines -take them, don't waste them!

This issue, consultant pharmacist Neil Hamilton has a very important message about prescriptions.



I hope that lots of readers will read the title of this article with horror, amazement and an honest sense of 'Neil's preaching to the converted'! However a couple of recent episodes have prompted me to remind everyone who is on medication, for whatever condition, that it is crucial you take it as prescribed or let someone know if you are not.

Any good prescriber, be it nurse, GP or one of the team at the hospital should take time to discuss and agree any treatment plan with you. This is a vital part of any consultation and the only way to ensure that everyone is happy with a new treatment.

The reality we find is that all too often patients are unsure which tablet is which and what each of them is for. Anyone suffering from multiple medical conditions or with memory problems may find taking lots of different medicines difficult. If this is you, have a chat with your local pharmacist about the different tools and systems they can offer you to help.

'Non-compliance' is the name given to the situation where a patient is not taking their medicines as prescribed. There are at least two consequences of this; firstly, clinical impact to the patient and secondly, medicine waste. Usually these go hand-in-hand. I am going to focus here on the medicine waste aspect, but almost inevitably there will be an impact on the condition too. Medicine waste has hit the national news headlines given the amount of NHS resources involved. Some of you may have come across the photo below on social media showing medicines found at someone's house when they had sadly passed away.

Anyone interested in reading further should have a look at www.medicinewaste.com



The website quotes that unused prescription medicines costs the NHS an estimated £300million every year. They equate this to 11,778 more community nurses or 80,906 more hip replacements.

It struck me as a hugely worthwhile campaign and the website describes lots of ideas of how you can help:

ONLY ORDER THE MEDICINES THAT YOU NEED

- Please let your GP or pharmacist know if you've stopped taking any of your medicines.
- Check what medicines you still have at home before re-ordering.
- Discuss your medication with your GP or pharmacist on a regular basis.
- Think carefully before ticking all the boxes on your repeat prescription forms and only tick those you really need
- If you don't need the medicine please don't order it! If you need the medicine in the future you can still request it.
- If you need to go into hospital, please remember to take all your medicines with you in a clearly marked bag.
- Please also remember that your medicines are prescribed only for you; it's not safe to share them with anyone else.

REMEMBER THAT UNUSED MEDICINES CANNOT BE RECYCLED

- Even if you never open them, once medicines have left the pharmacy, they cannot be recycled or used by anyone else.
- Please bring your unused medicines to the pharmacy for safe disposal.
- NEVER dispose of your unused or unwanted medicines down the toilet.

UNUSED MEDICINES ARE A SAFETY RISK

- Return out-of-date medicines to your pharmacy or dispensary for safe disposal.
- If your medicines change - return your old medicines to the pharmacy for safe disposal to avoid mixing them up with your new medicines.
- Don't stockpile medication - it is a safety risk for children and others who might take them.
- Store medicines in an appropriate place out of reach of children.



We recently saw a pertinent example of medicine waste on a huge scale in our PH clinic in Sheffield. You can see in the photo above how much nebulised iloprost was returned unused to us – almost 10 months' worth, and nearly £30,000 in value.

Reducing medicines wastage is everyone's responsibility. Healthcare resources and prescribing budgets are limited and becoming ever more so in the NHS and indeed worldwide. We need to all do our bit to ensure that waste is kept to an absolute minimum.

In the context of pulmonary hypertension, we are required to show the financial impact of any new treatment that we want to access, for example recently, selexipag. Being able to prescribe new treatments as they are licensed relies on us being responsible with them.

Ultimately, the treatments we use in PH will control symptoms and slow progression of the condition. Hence if the treatments you are prescribed are either not tolerated or ineffective, you must discuss this with the team at your specialist centre. Please don't continue to accept homecare deliveries and build up a stockpile.

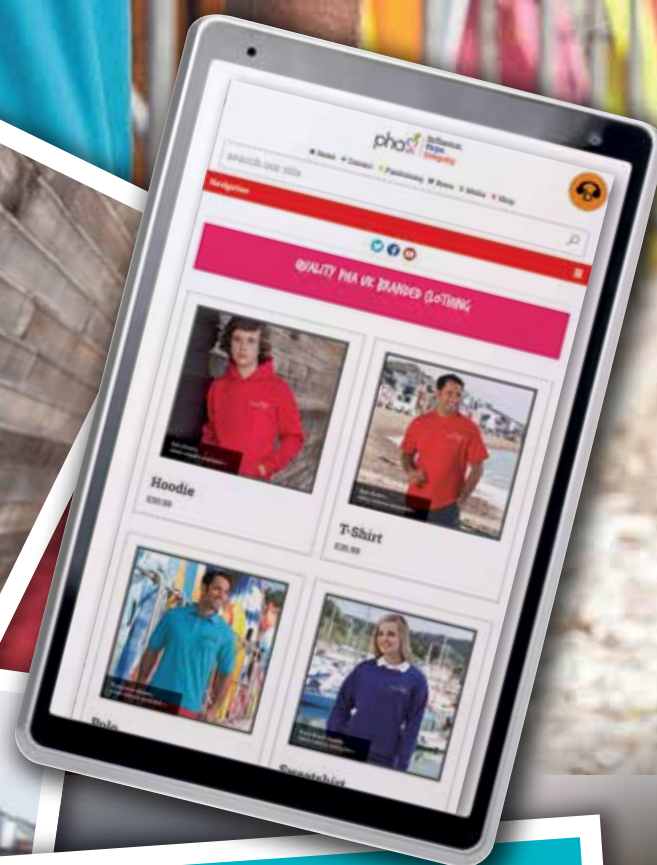
Please also be really honest in the clinic – don't be afraid to tell us that you aren't taking your medicines as prescribed because we can then discuss and agree other options with you. We are here for your benefit! ●

Fly the flag for PH awareness in one of our new PHA UK tops...

Choose from t-shirts, polo shirts, sweatshirts and hoodies, for adults and children in a range of colours.

30% of all clothing sales go towards the PHA UK's charitable activities

pha UK Influence Hope Integrity



Order online

www.phauk.org/shop
or call 01709 761450

Don't forget your flu jab!

Colder weather is on its way and if you have PH, it's vital you get your flu vaccine.

Where?

You can get your vaccine free on the NHS at your GP surgery or a local pharmacy offering the service. Some community pharmacies now offer flu vaccination to adults at risk of flu, including people with long-term health conditions and carers. If you have your flu vaccine at a pharmacy, you do not have to inform a GP. It's up to the pharmacist to do that.

When?

The best time to have a flu vaccine is in the autumn, from the beginning of October to the end of November. But do not worry if you have missed it, as you can have the vaccine later in winter. Ask a GP or pharmacist.

Find out more about the flu vaccine at www.nhs.uk

An egg-free vaccine is now available



In your Winter issue of Emphasis...

The next issue of Emphasis is due out in December and planned content includes:

- Emotional wellbeing**
The results of our research.
- Online weight loss tools**
Helping you make and keep New Year Resolutions
- Safety at home**
Advice if you live alone

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

You can get involved in Emphasis too:

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

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

Join our PH family for free today

Be part of a 4,000-strong national support network.



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

Join today and benefit from:

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

Being part of PHA UK also enables you to participate in important research, and our friendly office staff are just one call away when you need advice. Join our PH family and you'll be joining 4,000 members in a unique network of support and inspiration.

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



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



Name: _____

Address: _____

Postcode: _____

Email: _____ Telephone: _____

Are you a Patient ☐ Carer ☐ Parent ☐ Medical professional ☐

Other (please state) _____

Are you willing to take part in PHA UK surveys? Yes ☐ No ☐

Which **specialist treatment centre** do you attend? _____

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



PHA UK Contact Details

Office hours: 9am to 3pm, Mon to Fri for general enquiries
Tel: 01709 761450
Web: www.phauk.org
Email: office@phauk.org
Address: PHA UK Resource Centre,
Unit 1, Newton Business Centre, Newton Chambers Road,
Thornccliffe Park, Chapeltown, Sheffield, S35 2PH
Registered Charity Number: 1120756

Anxiety UK

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

Turn2us

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

Do we have your correct details?

Please email us on office@phauk.org if any of the following apply to you:

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

Emphasis magazine is produced by PHA UK. Content by Capital B Media. Design by Creativesmith. This magazine is intended only to provide information and not medical advice on individual health matters. PHA UK will not be responsible for readers' actions taken as a result of their interpretation of this magazine. We encourage readers to always discuss their health with their doctors and medical team.

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