WINTER 2019

emphasis

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

The week we got #TogetherForPH

Looking back on PH Week '19

GREEN LEAF CREW

4-page pullout inside

THE EMOTIONAL IMPACT OF PULMONARY HYPERTENSION

Survey results revealed

Living later life with PH

Mick and Donald share their stories

YOUR DOUBLE GOLD AWARD WINNING MAGAZINE!

Plus...

Highlights of 2019 | National Audit of PH | Weight management | Expert interviews | ...and much, much more!

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Welcome

Welcome to the winter issue of Emphasis, bringing 2019 to a close.

What a year it's been! From our 20th anniversary conference to our recent PH Awareness Week, and so much in-between, it's been a special 12 months for the charity. We wanted to know your highlights too, and we celebrate them over on page 17.

We've packed our final issue of 2019 with plenty of news, features and advice; including the results of our research into the emotional impact of pulmonary hypertension. Almost 500 of you shared your experiences and the survey played a vital role in reaching the wider public during our awareness week. Once again, your voices have made a difference.

If you know any children with PH, you'll be pleased to know we have doubled the size of our Green Leaf Crew section and designed it as a pull-out, so it can be separated from the rest of the magazine. Please turn to the centre pages and share it with anyone you think may benefit.

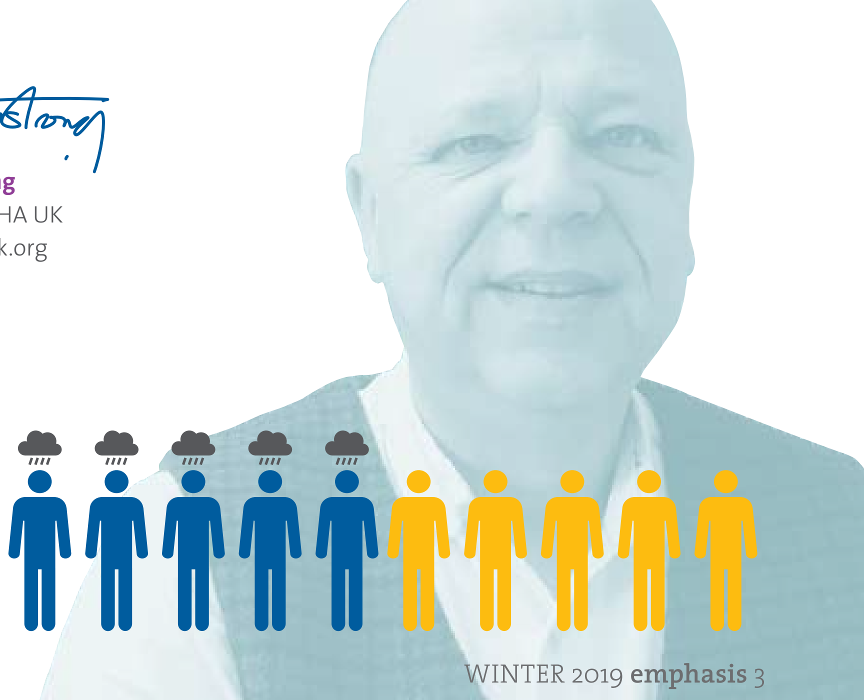
Finally, we're proud to say the magazine you're holding is now double gold-award winning, following the accolade of *'Best Publication'* – for the second time – at a prestigious awards ceremony last month. It's a fabulous way to end the year and I'd like to personally thank everyone who gets involved with making this magazine what it is.

Best wishes for a peaceful and enjoyable festive season and a positive start to 2020.

Iain Armstrong

Iain Armstrong
Chair of the PHA UK
media@phauk.org

> *"Once again, your voices have made a difference"*



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Richard looks back on his CTEPH diagnosis and surgery

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This magazine is printed on paper from sustainably managed sources

Emphasis **exchange**

Dear PHA UK,

I wanted to share a couple of photos of our big day. We had your pin badges as our wedding favours and we hope it raised awareness amongst those at our wedding who weren't aware of PH, as my husband's father passed away from it nearly nine years ago.

Many thanks again,
Stephie (and Richard) onley

If you would like to take inspiration from Stephie and consider our pin badges at your wedding please email **office@phauk.org**

DOUBLE GOLD FOR EMPHASIS

You're now reading a double gold award-winning magazine!

We were chuffed to bits when Emphasis was named 'Best Publication' at the 2019 Chartered Institute of Public Relations PRide Awards in November.

It follows success in the same category in 2017 and we'd like to thank everyone who contributes to these pages through sharing news, views, stories and advice. It's an award for us all!

Thank you to the family and friends of Asha Sagoo, who have donated £470 to the PHA UK in her memory. Asha was dedicated to raising awareness of PH and shared her organ donation and experiences in the pages of this magazine and with her local community.

Social Media Round-up

@katiedowling254
Lots of reading material for my train journey back to London. Great day in Sheffield learning from the fab @CarolKeenPhysio, talking all things PH and exercise. Thank you for having me! Looking forward to bringing some ideas back to @RoyalBrompton

Mitch Rumsey
I was diagnosed with PH 9 years ago. Still fighting and keep as active as possible. My motto? I don't live with PH. PH lives with me.

@LucillaPiccari
Not all difficulties and disabilities are evident from the outside. If in doubt, be kind. Not just with #PulmonaryHypertension but also in #life :)

@phighterbrooke
#throwback to when I was younger having canulas put in. I was #diagnosed with #ph when I was 6!!

Jane Grove
To anyone newly diagnosed, you are stronger than you think, keep positive, accept help (it is there), learn to love life again (just differently) X

@HIITorMISSUK (Gordon McGregor)
BBC here filming to launch the SPHERE trial during pulmonary hypertension awareness week

FOLLOW US...
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Twitter **@pha_uk**
Instagram **@pha_uk_insta**

Dr John Wort watching the presentations

Forum delegates showed their support for PH Week

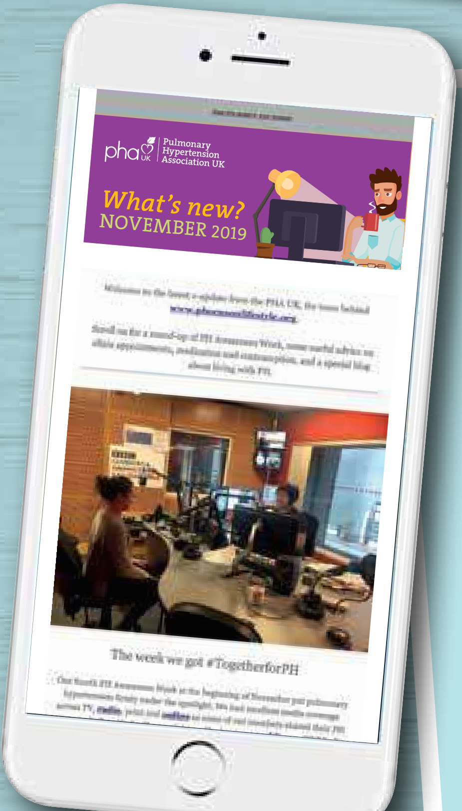
Supporting the future of research

It was an honour to provide the prize for 'best presentation' at the National Pulmonary Hypertension Research Forum in November.

Held at Chelsea Physic Garden, the annual forum brings together researchers and physicians from across the country and features presentations about new developments within the treatment of PH.

The prize, of covering travel expenses to an educational conference, was presented to medical student Angelos Anastasakis for his presentation about metabolic reprogramming of PASMCs in pulmonary arterial hypertension.

Look out for an article about his research in the next issue of Emphasis.



Pulmonary Hypertension Association UK

What's new?
NOVEMBER 2019

The week we got #TogetherforPH

KEEPING IN TOUCH VIA EMAIL

As well as this printed magazine, we also send regular e-newsletters with content from our sister website, phocusonlifestyle.org, and updates on important news and developments.

If you'd like to receive these updates, please make sure we have your email address. Simply email **office@phauk.org** with your name and the words 'Please sign me up to your newsletter' and we'll do the rest.

You can also send us a private message on Facebook, Twitter and Instagram.

We never use email addresses to ask for donations and we will never, ever pass your personal data to third parties.

That's a promise!

Paul joins the PHA UK team

We're delighted to welcome Paul Sephton to the PHA UK family. Paul has joined our small office team as Research Support and Development Coordinator and is working with us three days a week on specific projects to support the PH community.

Paul has 14 years of experience in the world of pulmonary hypertension, having recently retired from his role as Ward Manager at the Sheffield Pulmonary Vascular Disease Unit.

He said: "I'm passionate about supporting people with PH and this position is a fantastic opportunity for me to continue helping patients and their loved ones outside of a clinical environment. The PHA UK team have made me very welcome and I'm really looking forward to settling in and developing my role here at the charity."

Dear PHA UK,

This is Josie. She was diagnosed when she was just eight months old, but thanks to the wonderful team at GOSH she is now six, going from strength to strength and enjoying school. We wanted to share our story to give everyone some hope. Yes pulmonary hypertension is horrible and scary, but it also makes a child a mighty strong warrior!

Natasha Rich,
Josie's mum

Last minute Christmas shopping online? No matter what gift you're giving, you could raise an extra gift for us for FREE! Click via Give as you Live before you shop, and the retailer will pay us a percentage of your transaction as a donation, at no cost to you! Here's the link to click: https://bit.ly/2BlfCHo

Breathless not voiceless

Almost 500 PHA UK members shared their experiences of the emotional impact of PH in a major survey over the summer. Here, we bring you the findings.

92% of people with PH say the condition has ***affected their emotional wellbeing.***

LIVING WITH PH
THE EVIDENCE | 2019
Beneath the surface
The true emotional impact of pulmonary hypertension.

More results over the page >>>

> *Until you've walked in the footsteps of someone with PH,* ***you're never going to know what it's fully like.***

Paula Hartley
diagnosed with PH in 2007

Pulmonary hypertension comes with many challenges, and not all are physical.

Of those who responded to our 2017 Living with PH survey, 87% said the condition impacts their mental and emotional wellbeing – and we wanted to know more.

This follow-up research drew 498 responses, the second highest ever response rate to a PHA UK survey. This number in itself tells us how important the subject is.

The results are powerful, but not surprising. We have always known that pulmonary hypertension affects mental and emotional wellbeing, and these findings now provide vital statistical evidence.

As a patient organisation the PHA UK has long recognised that our members have emotional needs too. That's why, in 2012, we partnered with Anxiety UK to provide a specialist helpline service that enables those struggling to access advice and support. You can find out more about this on the page opposite.

Mental health and emotional wellbeing is being talked about more and more, and the stigma is starting to lift. For people affected by PH, we hope this research will show them they are not on their own.

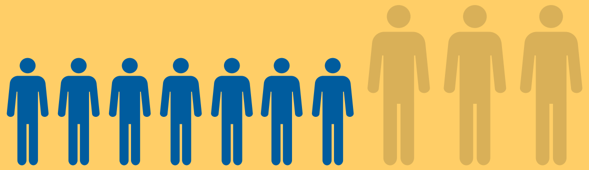
Iain Armstrong

Iain Armstrong

Chair, PHA UK.

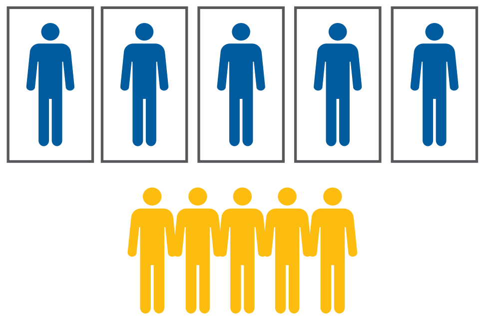
53%

of people diagnosed with PH have experienced or been diagnosed with ***anxiety or depression.***

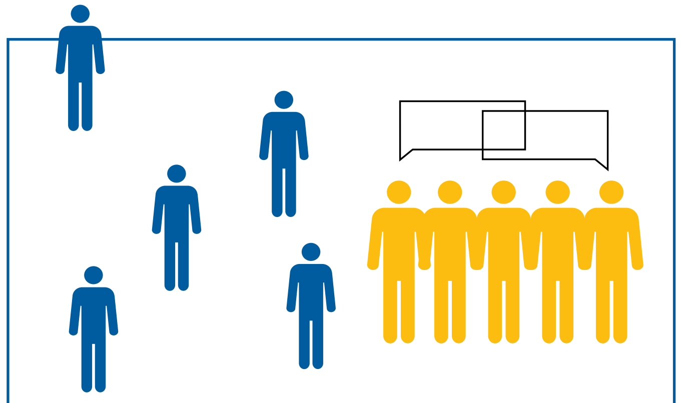


70%

of people with PH say the condition has ***lowered their self-confidence.***



49% of people with PH say the condition makes them ***feel isolated.***



53% of people with PH say the condition makes ***socialising difficult.***

43% of people with PH say the condition makes them ***feel lonely.***

58% of people with PH say the condition has ***changed their role in the family.***

58% of those who have experienced or been diagnosed with anxiety or depression have ***asked for professional help.***

LIVE BETTER WITH PH

THE EVIDENCE | 2019

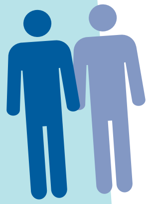
Beneath the surface

The true emotional impact of pulmonary hypertension

Beneath the surface: The true emotional impact of PH

We've produced a special report that highlights the findings from the survey and shares the stories of people living with PH. Order your free copy at www.phauk.org or email office@phauk.org

** Support is available if you are struggling with the emotional impact of PH. Please see page 10 for information about our partnership with **Anxiety UK**.*



MORE THAN NUMBERS AND STATISTICS.

To bring the findings to life, we filmed interviews with five PHA UK members, and their loved ones, to highlight their personal experiences of the emotional impact of PH.

You can see the films by visiting www.PHocus2021.org or the PHA UK YouTube channel.

PH AWARENESS WEEK 2019

The week we came #TogetherForPH

Thank you to everyone who joined us for PH Awareness Week 2019

Our annual campaign in November saw the PH community join forces to shout from the rooftops about our little-known disease.

We used the week to share the findings of our research into the emotional impact of PH (see p11) and released special videos to help the wider public understand. Thank you to those who shared their experiences in these films; you'll find them all on our YouTube channel at ***youtube.com/user/phaoffice***

A picture paints a thousand words and with so much going on during PH Week, we thought we'd share some of the highlights below...

Social media superstars

It was great to see so many people (and pets!) using our photo cards to share images on Facebook, Twitter and Instagram.

Get-togethers

Across the country, the PH community took the opportunity to get together for Tea & Talk and Darts & Drinks events, making good use of our special bunting, posters, flags and flights.

tea&talk ABOUT PH

darts&drinks FOR PH

Little PHighters

We dedicated Saturday 9th November to celebrating children living with pulmonary hypertension. Here are just a few of the smiles we shared...

Media mania

From TV and radio interviews to newspaper features and online articles, we saw people affected by PH share their stories with media outlets up and down the country.

Pledges for PH

Our new online pledge wall saw dozens of patients, supporters, healthcare professionals and MPs come together to make promises for PH. There's still time to make yours – visit www.phocus2021.org and follow the link on the homepage. You can view the pledges online too.

Support from professionals

From the National PH Research Forum conference to the wards of the Sheffield Pulmonary Vascular Disease Unit and the cake sales of Papworth - and much more - we saw some fantastic support from healthcare professionals in the field of PH.

The week also saw people write to their GPs to promote our medical education programme, put up posters, hold fundraising events, create blogs, and much more.

Thank you to everyone who got involved and let's keep those conversations going!

PH AWARENESS WEEK 2019

Liesl Andersson from Kent was told she had idiopathic pulmonary hypertension in November 2014, so PH Awareness Week marked five years since diagnosis. She wrote this blog to support our campaign and help people to be more understanding of those with hidden disabilities.

Liesl's blog was published on our lifestyle website, **www.phocusonlifestyle.org**. If you would like to submit a blog for publication, please email **media@phauk.org**

www.phocusonlifestyle.org

"However well someone looks, you don't know how they feel inside"

"In the beginning it was a real emotional rollercoaster.

There were lots of dark thoughts, and I was convinced I was going to die. When I got my diagnosis, I asked what my prognosis was, and I was told I had a 50 per cent chance of lasting ten years. It's weird, because then you hang everything on those ten years.

At the last appointment I had, because my meds are working so well and my heart has recovered a lot, I asked again what my prognosis was and was told they couldn't put a number on it anymore. They said there's no reason why I shouldn't live as long as the meds are working and they can't possibly know if and when they might stop.

I do worry about what the future might hold. I don't want to suddenly find that everything is going downhill. I know there is a lot more medication I can go on, but it's still a massive worry. It's the not knowing that I find difficult, as different medications affect people in different ways and everyone seems to have a different journey.

In many ways I'm really lucky because I'm responding well to the meds and am able to hold down a full-time job as head of sixth form at a special school.

But having PH does still affect me and I never know what will change in the future.

I think emotionally, the thing I struggle with the most is that everyone is always telling me how good I look, and how well I'm doing - so it's really hard to say 'I actually feel awful today'. I think PH has affected my self-confidence, certainly at work.

The main message I want to get across to the wider public is not to be judgmental. Be understanding, and don't avoid asking people how they are. However well someone looks, you don't know how they feel inside.

PH is such a little-known condition, so I just want people to be aware that not everybody is what they seem to be. As with everything in life, empathy is the key."

Liesl and her daughter Billie

Celebrating 2019

2019 marks two decades since the PHA UK was formed – and what a year it's been!

We've ended the year with over 4,500 members; a growing army of phighters forming a unique community of support. Our members have always been at the heart of what we do, so we've dedicated this page to your 2019 highlights, rather than ours.

Here's what you told us on Facebook...

Karen Louise Salter
My highlight is feeling like I'm living life again, after 12 months of feeling so unwell... Thank GOODNESS for Papworth, targeted therapies, oxygen at home and my GORGEOUS husband Kevin

Jane Barker-Benfield
My highlight was being able to go on holiday to the stunning Scottish Highlands. Prior to my diagnosis and starting treatment last year I didn't think it would ever be a possibility. I can't thank the team at the Brompton enough.

Brooke Thompson
Going to Great Ormond Street a few weeks ago and being told that my MRI scan had improved from the last one!!

Judy Bugg
Biggest highlight ever was my two new grandchildren born January and February, just a week apart. And having no infections all year which is a first for me, so I have been able to make the most of it.

Lorretta Walsh
My highlight this year was finally getting a diagnosis after so much uncertainty, and feeling well enough to commit to getting another rescue dog. Xx

Mary Clements
Watching my husband Alan Clements walk our daughter down the aisle in May. In 2016, we weren't sure he'd survive the year after his PAH diagnosis

Sharon Green
Our daughter (Lauren) graduating as a teacher and starting her first job (cue VERY proud parents)

Paula Massie
Having my double lung transplant in May. Thanks to the teams at the Scottish Pulmonary Vascular Unit and Freeman Hospital for looking after me xx

Jules Smith
My highlight will be my daughter's marriage in 12 days. I never thought I would make it this far and I am so happy and feel so blessed that I will see her marry

Carmel Warner
My highlight is my two new grandsons, born 2 months apart, and not forgetting my 7-year-old granddaughter x

My life-changing exercise journey

Nasreen Bi may not fit the 'gym bunny' stereotype on paper, but getting active has seen the 43-year old from Birmingham lose 30kg and live a happy family life. She told *Mary Ferguson* about the turning points which helped her get there.

New mother Nasreen was diagnosed with idiopathic pulmonary hypertension in 2010 and her introduction to the power of physical activity came straight away.

A delayed diagnosis led to an emergency hospital admission and by her third week of being in bed on the ward, she was so weak she needed help to move.

"The doctors told me I wouldn't be able to go home until they could see I could move and do things", said Nasreen. *"That was my motivation to get up.* ***I had a baby at home, and another son, and I didn't want this to beat me. I put one step in front of the other and from that day I started walking.****"*

Once home, her family wanted to do everything for her, so she spent most of her time sitting down. Her only activity was taking her son to school and sedentary life continued.

Taking part in a pilgrimage was the first turning point for Nasreen. She joined her family on the Hajj to Mecca, taking her wheelchair with her, and realised what determination could do.

"It was hard, but I felt I had been called by Allah to perform the pilgrimage, and by his grace, I was fine."

The year after returning from Hajj, another experience gave Nasreen the final push to get fitter.

With her breathlessness getting worse, she was assessed for a lung transplant and told that although she was too well to be listed, her Body Mass Index (BMI) was too high to have the surgery if she needed it.

"I walked out that day in 2016 and decided I really needed to do something."

Nasreen visited her GP to ask for help with losing weight and was given an 'exercise prescription' – a free 12-week membership to her local leisure centre with specialist instructors on hand to help her.

"I was determined to do it. I had my induction at the gym, and three years later, I'm still at it. It was hard at first, but I have lost around 30kg, and managed to keep it off."

Nasreen started off taking part in Zumba (dance fitness) classes but felt the pump for her Hickman line prevented her giving it her all. Now, she mixes workouts with 'Body Pump' classes, performing the movements without weights if she needs to.

Her gym routine normally involves 10-15 minutes of walking on the treadmill, followed by the cross trainer, rowing machine and bike. The resistance levels are kept low, with the focus on the movement.

Nasreen has created an exercise schedule she can stick to by recognising the time of day that works best for her. *"I never have any energy in the evenings, so it's always in the morning when I go. And that's when my boys are at school too."*

With her passion for exercise rubbing off, Nasreen's husband now joins her at the gym and they do their workouts together. She recognises that not all women of her faith would feel comfortable, but she's found a lifestyle that works for her.

"You tend not to find too many Asian women in a mixed gym, but I don't care", she said. *"The younger generation seem not to mind so much. You don't need to wear tight gym clothes; you can wear what you want. I tend to wear tracksuit bottoms and a top, and I tuck my pump under my outfit where it's secure, then just carry on. I don't think I could run on the treadmill with it, but I'm fine if I stick to walking."*

As well helping to dramatically reduce her body weight, Nasreen says the exercise makes her feel better mentally too.

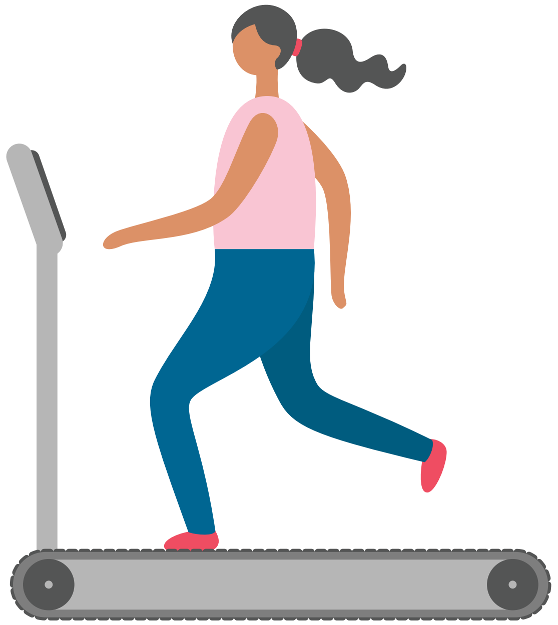
"I almost forget I'm ill now. I feel good when I've been to the gym and if I can't get there, I miss it. I have to stay active; if I sit down all day, my body starts to ache.

"I understand that if you have PH it can feel scary to exercise. But if you believe you can do it, you can, and I like to encourage people to try."

Nasreen believes that if she hadn't had a wake-up call when she went for her transplant assessment, things would be very different.

"If I hadn't been told to lose weight, I would have just carried on sitting on the sofa saying 'I have an illness'. I think sometimes, you just need to be told. The fear of not being able to have a transplant if I needed one made me do it. I had to do it for my children." ●

> “I understand that if you have PH it can feel scary to exercise. But if you believe you can do it, you can”



Always talk to your PH specialist before starting an exercise programme. For help and advice, please visit **www.phocusonlifestyle.org** where you'll find a number of PHA UK produced video resources designed to help you get fitter and stronger with pulmonary hypertension.

THE NATIONAL AUDIT OF PULMONARY HYPERTENSION 2019
KEY FINDINGS

ANNUAL
REPORT

NATIONAL AUDIT OF PH ENTERS ITS **TENTH YEAR**

The National Audit of Pulmonary Hypertension was created ten years ago to collect and report on data across all specialist PH centres in the UK, with the aim of improving patient care and informing future service planning.

The PHA UK played an important part in funding the creation of the audit, and since then, we have continued to provide support and advice to the audit funders, the NHS Special Commissioning in England, and to NHS Digital – which manages the development of the audit each year.

In this issue of Emphasis, we bring you the key findings from the tenth National Audit of Pulmonary Hypertension published in October, which you told us were most important to you. The audit data covers the period of 1st April 2018 to 31st March 2019.

Despite the many pressures facing the NHS, the audit evidences how well the specialist centres are performing.

We hope the findings are easy to digest and provide you with a clear picture of what's going on nationally.

If you think we could present the key findings in a different way, or if there is something you would like to include in future reports, please do let us know. Call us on 01709 761450 or email office@phauk.org

We hope you find the key findings useful.

Iain Armstrong

Iain Armstrong,
Chair of the PHA UK

In 2018/19 data for the national audit was submitted by all eight specialist PH centres in England and Scotland.

- Golden Jubilee National Hospital, Glasgow
- Hammersmith Hospital, London
- Papworth Hospital, Cambridge
- Royal Brompton Hospital, London
- Royal Free Hospital, London
- Royal Hallamshire, Sheffield
- Freeman Hospital, Newcastle
- Great Ormond Street Children's Hospital, London

The four highlighted findings opposite were selected by people with PH as the most important to them. The percentages shown are an average across the centres. We have compared the findings to last year, as well as highlighting the professionally agreed standards that the centres are expected to meet.

How many patients, who have had at least one consultation in the last year, have had a quality of life questionnaire recorded during that time?

96%

90% TARGET

SAME AS LAST YEAR

How many patients taking PH specific drugs have had a least one annual consultation at a specialist PH centre?

96%

90% TARGET

SAME AS LAST YEAR

How many patients referred to a specialist centre were seen, assessed and diagnosed within six months?

99%

95% TARGET

+1% INCREASE ON LAST YEAR

How many patients received a right heart catheterisation before being given drugs to treat PH?

97%

95% TARGET

+1% INCREASE ON LAST YEAR

The National Audit also discovered that between 1st April 2018 & 31st March 2019:

8,351 patients were managed by PH centres (7,670 last year)

97% of patients had a WHO functional class and six-minute walk or shuttle exercise test recorded before being given drugs to treat PH. (98% last year)

63% of patients referred to a special centre attended a consultation or were discharged within 30 days. (60% last year)

100% of patients receiving drug treatment for PH had an official diagnosis recorded. (100% last year)

91% of patients received first line drug therapy of phosphodiesterase 5 inhibitor. (93% last year)

The full National Audit of Pulmonary Hypertension, including all the findings, is available by visiting www.digital.nhs.uk/pubs/naph10

SUPPORTING A SISTER WITH PH

Mark Stanley from Derbyshire has made it his mission to fundraise for the PHA UK after his sister Kelly was diagnosed with PH in 2011. Here Mark, 41, shares the story of Kelly's bravery, how the family have supported her, and his determination to raise awareness of pulmonary hypertension for his sister.

“My sister Kelly doesn't shout about having PH. She uses social media to raise awareness, but she doesn't complain about how it affects her or try to get sympathy from people. She's very brave and she just gets on with it. But I know that a lot of people don't know anything about pulmonary hypertension, so I feel it's important if I can help with raising awareness.

Kelly has always had problems with her heart. When she was born in 1974, we nearly lost her to pulmonary atresia. Then when she was ten years old, she was sent home to die because of her congenital heart disease; there was nothing more the specialists could do for her. But my mum refused to accept that and wrote to everyone she could find to see if they could help. In the end an American surgeon operated on her at Liverpool hospital which saved her life. In 1994 she had meningitis which was caused by an infection in her heart, but she made it through; she's a fighter! Then in 2011, she was diagnosed with pulmonary hypertension.

Because Kelly has had very serious illnesses since she was born, the PH diagnosis didn't come as a huge shock. She takes everything in her stride and just gets on with her life. One example is when we went down to London to see Blur not long after she had recovered from meningitis. In hindsight it was a terrible idea because it was an open-air gig, and Kelly ended up going to hospital because she became too cold. She was not well enough to be there, but because we both wanted to go so much, we went anyway. We made it back to the gig for the last song! I think she deserves recognition for her bravery because I don't know how I would cope with the illnesses that Kelly has had through her life.

There has obviously been an impact on the family. Kelly lives with our mum and dad and she has a very special relationship with them, they're like The Three Musketeers! They do everything together, enjoying trips to London and Brighton and it's a very happy household.

Kelly was last in hospital just before Christmas in 2018 with heart failure. She was given an intravenous line and diuretics to stabilise her. It was a real wrench on the family and obviously we were concerned. But Kelly doesn't make a fuss and is very conscious of worrying other members of the family. I remember her showing me the letter from the consultant and saying, ‘don't worry, my heart didn't fail, it just isn't quite working properly’. She's always been quite protective of us in terms of disclosing details.

> “Fundraising seems like something I can do which will genuinely make a difference.”

When the family is together, Kelly's health is not something we ever really discuss because we like to concentrate on enjoying our time together. I think that's why I feel like fundraising is an important thing to do; I don't feel as though I do anything significant to help Kelly because she doesn't expect anyone to treat her differently. I take my four-year-old daughter Ada to see her every week, but I would do that anyway even if she was perfectly healthy because we have always been very close. I think if it was up to her, nobody would know she had PH.

I've fundraised for other charities in the past, so supporting the PHA UK seemed like the obvious thing to do following Kelly's diagnosis. Last year I completed a 50k walk in 12 hours across the Peak District, which was pretty tough as I ended up doing it on my own and got chased off the route by three farm dogs! I had to miss the organised event because I was ill when it took place. It felt like an appropriate thing to do because one of the impacts of PH for Kelly is that she can't walk any sort of distance without getting tired.

> *“Kelly takes everything in her stride and just gets on with her life because it's all she has ever known.”*

My next challenge is to climb Ben Nevis next year. I was inspired by one of Kelly's consultants who said that the stress her breathing puts on her body is similar to what a healthy person would experience on Everest. I'm not fit or brave enough to climb Everest, but Ben Nevis is the highest peak in the UK, so I think it still represents that same concept.

When a loved one has a really serious illness, ultimately there's not a lot you can do. But fundraising seems like something I can do which will genuinely make a difference, not just to Kelly but to anyone who is living with PH. The community aspect of the PHA UK has been important to her – being aware of people with the same condition has helped her because when you've got something as rare as PH, I imagine it can be hard living day-to-day thinking that only you are suffering with it. Through the PHA UK Kelly has been able to reach out to other people and be reassured that she isn't alone.”

To sponsor Mark on his Ben Nevis climb, search ‘***markbennevis***’ at www.justgiving.com

Changing direction

When *Katie Somerfield* was diagnosed with idiopathic PAH in 2015, she would never have believed that four years later she'd be embarking on a new career in healthcare. Here, the 35-year-old from Newport tells Emphasis about the Physician Associate Masters course she started this autumn.

Having come to terms with my PH diagnosis and not being able to have children, I came to realise that I wanted to dedicate my life to helping others.

Having explored how I could do this for the past two years, whilst it was possible to become a doctor, this would have had large financial implications and taken many years to accomplish.

I attended an open day at Swansea Medical School and felt inspired by a talk on the Physician Associate Masters. This was a funded course which resulted in working in the NHS, with opportunities across many areas of healthcare. The role of a Physician Associate is similar to that of a junior doctor, where you work supervised, and includes managing patient lists - whether this be in A&E through to surgical placements or having your own clinic in a GP surgery.

In 2018 I gave up my career in marketing and event management to gain experience of working in a healthcare setting, so I could understand the nature of what I was stepping into.

I went on to undertake an A-level maths equivalent as the university had certain requirements for applicants, and I also spent some time interviewing many healthcare professionals, including a midwife, consultant, junior doctor and paramedics.

I worked hard to get through the application and was overjoyed to hear I had made it through to interview stage. I had to fill in a disability form where I told them I had PH, and the form required a letter from my doctor. I also had to undergo a medical assessment.

I started the course this autumn and it includes 1,600 hours of clinical placements across GP surgeries and rotations around hospital areas in addition to classroom-based learning.

I will use the tools I have developed to support myself through the stress that will come with such an intense course.

These tools include meditating, yoga, exercising, maintaining a strong social network, my Buddhist practice and going out into nature as often as possible.

I believe that these aspects of health, which sometimes fall under the remit of 'social prescribing', an area I'm really interested in, are as important for keeping me relatively well as the medicine I take every day.

When I was first diagnosed with PH, I couldn't have imagined that just a few years later I would be training to become a Physician Associate. I'd been climbing the marketing career ladder, enjoying a high salary, and I never would have thought I'd end up in a medical or caring position.

I believe everything happens for a reason and that I'm capable of handling whatever life throws at me. I've spent a lot of time grieving for the children I won't have, for the years of life I may have lost, and the limitations of PH – but I am incredibly happy to say that I feel very positive about where this has now led me.

If it wasn't for PH, I would have spent many years working in a soulless career I had come to hate; being part of the rat race and feeling dissatisfied at the state of the world.

Whilst I wouldn't wish PH on anyone and I am still hopeful for a cure, I know that this journey has enabled me to spend the rest of my days focused on helping other people. That, for me, is the meaning of life. ●

Contraception & pulmonary hypertension

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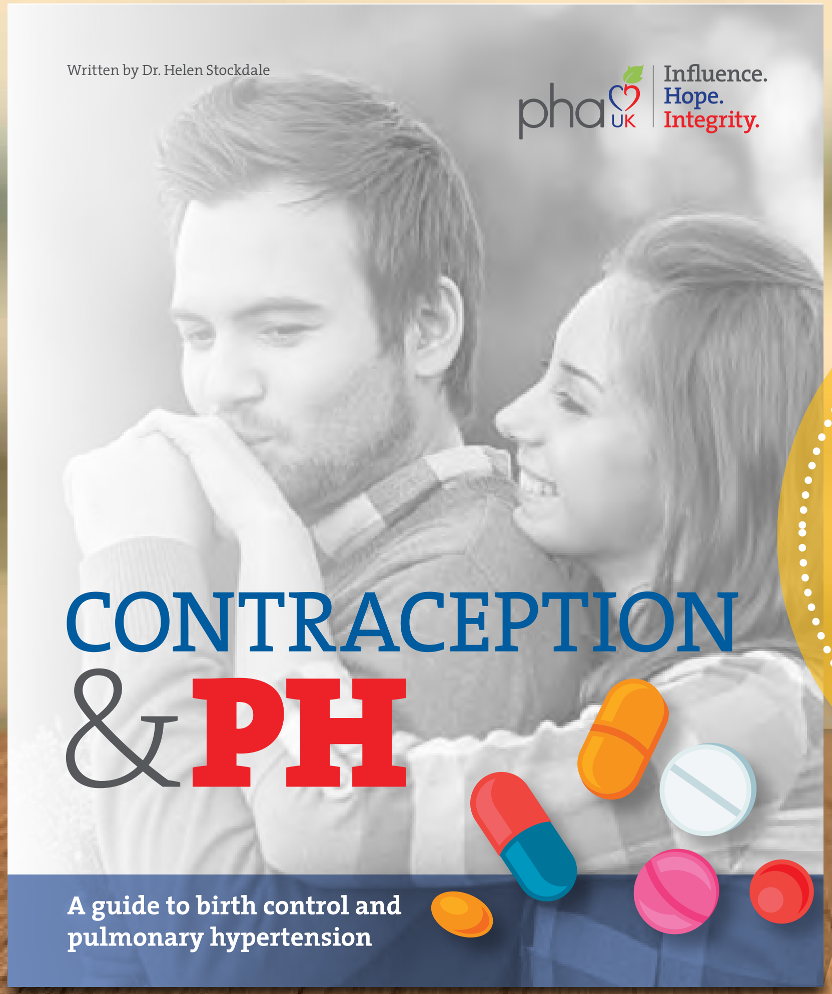

Written by Dr. Helen Stockdale

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CONTRACEPTION & PH

A guide to birth control and pulmonary hypertension

FREE GUIDE

Green Leaf Crew!

NEW! BIGGER 4-PAGE PULL-OUT

Kaylee's tips for GOSH trips...

Kaylee Mynot from Surrey is 19 years old and was diagnosed with PH as a baby. Kaylee has had many trips to Great Ormond Street Hospital, so here she shares five tips to make your clinic visits as comfortable as possible.

Bring something to keep you occupied

"Whether it's a good book, an iPad, or even a notebook computer, take something to keep your mind occupied while you are waiting. Also remember earphones!"

Wear comfortable clothing

"This is especially important for girls. When you go into clinic, wear comfortable, loose-fitting clothes. You will have to take your clothes off if you have a scan so wearing loose-fitting items makes that easier."

Explore the hospital

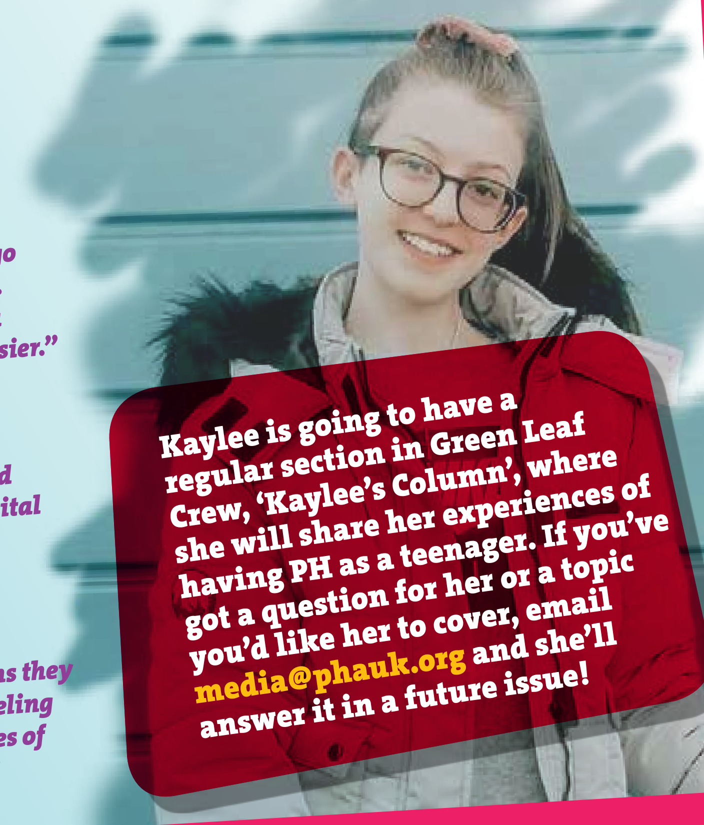
"You could visit the Activity Centre, which has something for all ages including games, arts and crafts, IT equipment and books. The entire hospital also has free Wi-Fi!"

Tell friends and family about your visit

"Telling your loved ones about your visit means they will send you messages of support. If you're feeling nervous in the waiting room, reading messages of good luck might make you feel more relaxed."

Wear beads of courage

"Every time you have tests or scans, add a bead to a ribbon. Then for bigger procedures you have bigger beads so when you look back, you can see how much you've overcome, and your beads of courage will just keep growing."



Kaylee is going to have a regular section in Green Leaf Crew, 'Kaylee's Column', where she will share her experiences of having PH as a teenager. If you've got a question for her or a topic you'd like her to cover, email media@phauk.org and she'll answer it in a future issue!

New year's resolutions...

by David Banks

My little life with PH...

Hi, I am Emily and I am nine years old. I have PAH and am looked after by the brilliant PH team at GOSH. I live near Newbury, so it takes me and my mum at least two hours to get to London! I can't do a lot of running around because my PAH makes me get out of puff quite quickly. I love my visits to GOSH because there are lots of lovely nurses and doctors there. There is a Disney reef and sometimes you can do crafts in the Lagoon. I also like going to the GOSH shop and trying to convince my Mum to buy me something nice! I always succeed! In my spare time, I go to Stagecoach (theatre school) for three hours on a Saturday afternoon and do dance, acting and singing classes there. I play the violin and I passed my grade one exam with merit last summer. I play percussion in my school's brass band. I go to lots of school clubs including Bananagram, choir, art, knitting dance and writing club.

If you are a young person with PH who would like to write about life with PH, ask an adult to send an email to media@phauk.org

SCALING SNOWDON WITH PH

Teenager Rachael Emery climbed Mount Snowdon four years after being diagnosed with PH, raising over £2000. Rachael, 15, and her mum Helen, tell the inspirational story.

RACHAEL AT THE SUMMIT WITH HER BROTHER TOM.

Climbing Wales' highest mountain is a tiring task for even the fittest of people, so when Rachael Emery made it to the summit with a Hickman line, it was an enormous achievement. Rachael, from Bewdley in Worcestershire, climbed Snowdon with her brother Tom and dad Jools, just four years after being diagnosed with PH and connective tissue disorder.

"I had to deal with 60mph winds so that made it harder," Rachael said. *"When I got to the top, I felt so proud of myself but to be honest I just wanted to get down, it was too windy!"*

Rachael's mum Helen said: "When I think about the journey she's been on, from hardly being able to walk at the beginning, I feel super proud of her – it's unbelievable. She will not let anything hold her back from enjoying life, despite all that she has been through."

Rachael was taken to Worcester hospital in December 2015 when she noticed swelling in her stomach and ankles. She was transferred to Birmingham Children's Hospital and then Great Ormond Street - where she was diagnosed with pulmonary arterial hypertension (PAH). She was not responding well to treatment - so she was sent to the Royal Free Hospital for a second opinion.

"Dr Schreiber at the Royal Free was absolutely fantastic," Helen said. *"They found that Rachael had connective tissue disorder, and they gave her six infusions of cyclophosphamide, which turned her into a different person. She could do all the things she used to do. She now has a Hickman line and is on Mycophenolate Mofetil, which is normally given to transplant patients, and it stabilises her PH."*

Raising money for the PHA UK was important to the family after the treatment Rachael received. *"The charity has done so much for people and I felt it was time to give something back,"* Rachael said. Fireglass UK, the employer of her dad Jools, donated £1000, meaning £2145 was raised in total. *"I never expected to raise so much – my target was £1000 so I was amazed when I'd more than doubled that."*

Helen is also grateful for the help of the PHA UK and the GOSH specialist team. "When you have a child who is diagnosed with PH, you feel alone because it's such an isolating condition," she added. "Dr Shahin Moledina, Dr Roberta Bini and Rebecca Turquet have supported Rachael and our family throughout her journey. The PHA UK has also offered a lot of support and it's comforting to know that they're there."

DID YOU SEE FOUR-YEAR-OLD LUCY HUNTER ON TV?

She has PH and was one of Paul O'Grady's Little Heroes, shown on ITV on 17 October.

You can still watch the show on the ITV Hub.

GREEN LEAF CREW Q&A

Ryley Maher

Ryley Maher is seven years old and lives in Woking with her mum, dad, big brother and Lucy the dog. Ryley was diagnosed with PH in July 2016.

Q. What's your favourite thing to do at school and why?

A. *I love science because you can investigate lots of different things.*

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

A. *Swimming with daddy or going to a restaurant - and loads more other things!*

Q. What's your favourite food?

A. *Pizza, but without cheese.*

Q. What's your favourite film or TV programme?

A. *I have lots - Teen Titans Go, Unikitty, The Amazing World of Gumball, Powerpuff Girls and Operation Ouch.*

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

A. *To be a doctor or scientist so I can make people better and find cures.*

Q. What do you enjoy most about Christmas?

A. *Presents, obviously!*

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

A. *Nobody, because I like being who I am.*

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

A. *Teleportation so I could go anywhere without needing to walk, which makes me tired.*

Spot the differences!

Can you spot the 6 differences in these two snowman scenes? Find the answers on page 49

PICS PLEASE!

On your next visit to Great Ormond Street, ask an adult to take a picture of you and email it to media@phauk.org for a chance to see yourself in the next Green Leaf Crew!

There was a large turnout to the last PH Professionals meeting in October

COLLABORATING FOR PATIENT CARE

There's a sense of community amongst the UK's specialist PH centres that's not limited to the individual hospitals - and the PH Professionals group is a perfect example of this collaborative way of working.

The next PH Professionals meeting takes place in March 2020

The PH Professionals is a multidisciplinary group, formed in 2011 and made up of nurses, pharmacists, physiotherapists, clinical psychologists and others from across the UK's specialist PH network.

Unique in its make-up, its core aims are centred around doing the best by patients. They include collaborating and sharing ideas; discussing issues surrounding treatments; developing best practice guidelines; discussing the mutual needs of the centres to influence commissioning on PH care and treatment, and developing and supporting collaborative multi-professional clinical research in PH.

The group is facilitated by the PHA UK, with funding provided by a consortium of pharmaceutical companies.

> ***"The meetings don't just tick boxes; they provide a unique and inclusive opportunity for collaborative working and sharing of best practice"***

It meets twice a year and conversations continue in-between via a dedicated website and email network.

Neil Hamilton, Consultant Pharmacist at the Sheffield Pulmonary Vascular Disease Unit, is Chair of the group and said its origins lay in the desire to ensure good quality and equity of care for patients across the UK.

"We wanted a forum that provided an opportunity for healthcare professionals from across the specialist PH network to meet up and share best practice, research ideas and collaborate to ensure people receive similar high quality of care and access to treatment wherever they go."

He added: *"The PH Professionals group has grown in every respect since its formation and has representation from an expanding range of professions. This range of expertise adds scope and balance to the group but, more importantly, has a growing impact on the care of PH patients in the UK."*

Meetings take place every six months in London and are preceded the evening before by a research presentation, ensuring continuous professional development for attendees and keeping them at the forefront of developments.

Iain Armstrong, Chair of the PHA UK, said: *"The PH Professionals meetings don't just tick boxes; they provide a unique and inclusive opportunity for collaborative working and sharing of best practice. And with the PHA UK as secretariat, the group engenders a central philosophy of patient-centred care - which is at the heart of the NHS."*

A separate group for consultants mirrors the PH Professionals group. With similar aims, they also meet twice a year.

Iain added: *"PH comes with many challenges and many uncertainties. What is clear, and very certain though, is that people living with the condition are supported by a dedicated, passionate and committed team of specialists who truly have patients at the heart of what they do."* ●

Living later life with PH

Pulmonary hypertension doesn't discriminate on age and maintaining hobbies and social interaction can be even more important as we get older. *Mary Ferguson* spoke to two pensioners making the most of their later years.

83

Mick Lovatt

Staffordshire-based Mick, 83, is no stranger to multiple health conditions. Diagnosed with pulmonary hypertension halfway through treatment for prostate cancer, he's now cancer free and determined not to be held back by PH.

"The main symptom I have is breathlessness," he said. ***"But I'm doing well on my tablets and I'm alright as long as I have a walking stick. If I get out of breath, I just stop and sit down for a bit."***

Maintaining an active social life is important to Mick. He is on the committee of a large club for pensioners, and they meet every fortnight at the local bowling club for bingo. During spring and summer, they go on monthly coach trips around the country, and Mick also helps organise events like pie and pea evenings, and parties for the over 80s.

On the weeks the pensioners club doesn't meet, he and his wife Dorothy visit their local pub for bingo. The pair also go out for lunch regularly with friends and spend time with family nearby.

"I get a lot of support from my family, they are brilliant," said Mick. ***"My sons help with jobs around the house and my daughter takes me to my appointments at my specialist centre as I don't like driving long distances now."***

Mick said his wife Dorothy is in 'reasonably good health' and they potter about in the garden together, sharing the work between them. ***"She does all the cutting down and that, and I do the planting. We try to keep busy. If we didn't, we would just sit and vegetate.***

"I still try to go to the football occasionally - Port Vale is my team - and I tend to go when the weather is good."

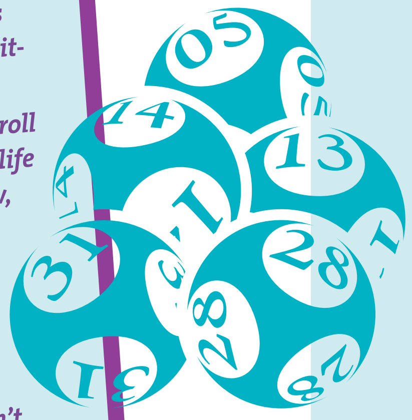
The couple enjoy short coach holidays around four times a year and are currently looking forward to a visit to Scotland in January. They take it steady when away, enjoying day trips and meals, and manage by doing things at their own pace.

"Mick can't walk up hills and things like that, but he has his stick and if he wants to sit down, we just do," said Dorothy. ***"Our friends are the same age as us, so they often need a sit-down too anyway!"***

"I manage the breathlessness ok if I just stroll about," added Mick. ***"You've just got to take life as it comes. If I can keep going like I am now, I'm happy."***

The pair have taken it upon themselves to keep busy and independent, sharing household chores between them and keeping in touch with friends.

"We've got very good family, but you can't rely on them all of the time, as they can't be with you all of the time," added Dorothy. ***"We've made a life for ourselves. Mick does very well, and we just keep going."***



73

Donald Whalley

As well as having PH, 73-year-old Donald lives with kidney failure – a condition which sees him travel to his local hospital for renal dialysis three times a week.

However, the grandfather from Greater Manchester doesn't let any of it get in the way of weekends away with his wife, and he even does his own decorating.

"I was diagnosed with pulmonary hypertension two years after starting the dialysis, so it has presented some additional challenges," he said. ***"I try not to let things get me down though – you just have to keep plodding on!"***

Donald's dialysis days start early. Every Monday, Wednesday and Friday he rises at 4.30am to get ready, taking regular breaks because of the breathlessness. Having long given up on patient transfer services, he drives himself to the hospital ten miles away, and uses an electric scooter to get from the car park to the ward.

The dialysis takes four hours, time which he spends watching TV, playing games on his tablet and chatting to the others around him. ***"I have a good natter about football with the chap opposite, and we're always winding the nurses up about Emmerdale and things on the telly."***

Donald's scooter has helped him maintain his independence, and he uses portable oxygen cylinders to ensure he can continue to get out and about.

"The scooter's a fold up one, very light, so I can lift it in and out of the car boot myself," he said. ***"My bottle sits between my knees and it all helps to keep me mobile."***

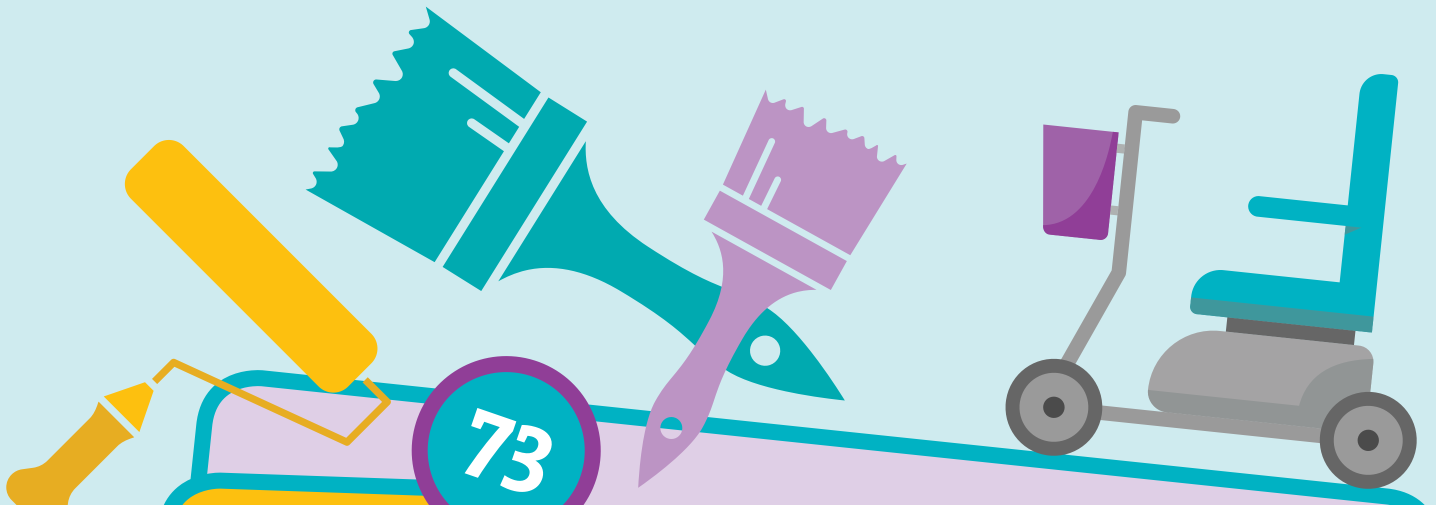
Once a fortnight, Donald and his wife Sandra visit their caravan near Blackpool, something they have enjoyed for the last ten years.

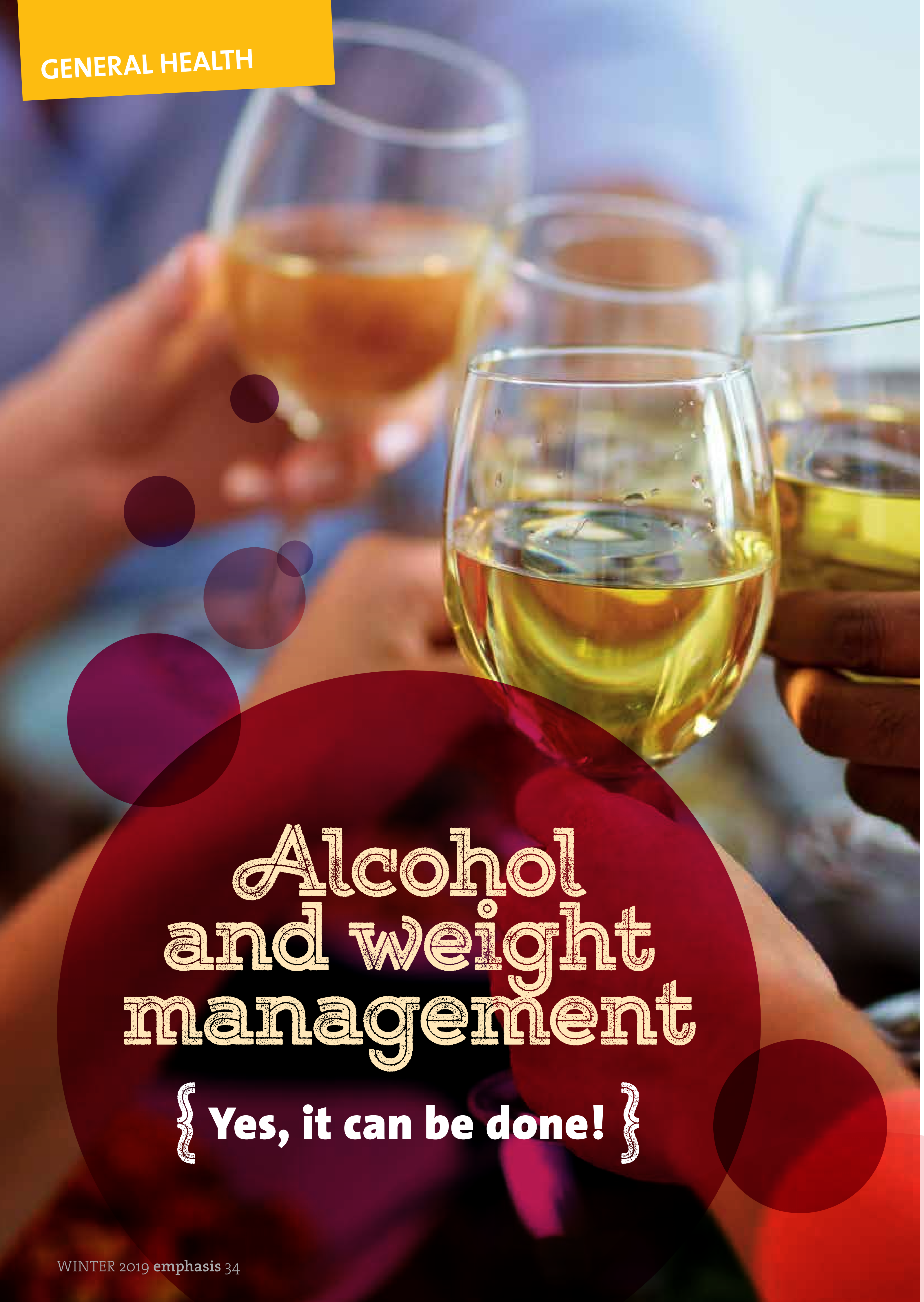
They also like to decorate and do things around their home – although Donald admits projects can take a while to be completed.

"It can take me all day just to move a curtain rail sometimes, but I keep going at it; I just have to do it in little stages. Sometimes the wife plays hell with me as I try too hard to do things, but I want to keep going. I do a bit, then have a sit down and get my breath sorted, and then do another five minutes."

Donald has five grandchildren aged between ten and 30 and as well as seeing them, he and Sandra enjoy shopping and occasional meals out together.

The pair do spend time on sedentary activities too. ***"When I'm not up at the caravan I enjoy watching sport on TV,"*** Donald said. ***"It used to be football, but now it's anything as I can get every sports channel going. Sandra and I also love watching quiz programmes and answering the questions. It's good for keeping the mind active!"***





Alcohol and weight management

{ Yes, it can be done! }

The festive season is upon us and drinks will be flowing. *Shaun Clayton*, Director of Membership Support at the PHA UK, explains how you can enjoy yourself whilst keeping an eye on your weight.

Before we get into the nitty gritty, it's important to say that if you have any questions or concerns about how alcohol could interact with any medication, please speak to a trained healthcare professional.

Socialising and seeing friends play a huge part in maintaining a healthy life, let alone diet. It's so, so important and is often one of the things to fall by the wayside when we start watching what we eat or drink. This then in turn leads us to feel rubbish about ourselves when we do drink, and often we just think 'sod it', have a complete blow out, feel the diet is ruined and give up entirely.

If that sounds familiar, read on...

Let's talk about energy balance. Alcoholic drinks, like everything, contain calories and how we decide to consume those calories is up to us. I wouldn't advocate making drinking a hugely regular thing if you're trying to diet, but just so you know, as far as your body is concerned a calorie is a calorie - whether it's coming from a potato, pick and mix bag, or a bottle of Bud.

(I probably need to mention, before you get too excited, that just because something may have the same caloric content, it does not mean that a bag of sweets is as nourishing as a potato!)

Imagine your body is a furnace and it doesn't care where the energy comes from, just so long as it can keep burning.

So, with this in mind, let's say you've got a night out with your partner, the girls or the lads this weekend. You're losing weight and everything's going great. What's the best thing to do?

Instead of thinking of your calories as a 'daily' allowance think of them as 'weekly'. If you were to have less calories per day leading up to your night out, maybe one slice of toast for breakfast rather than two, or skipping that biscuit with your coffee over the week, you'll have built up a calorie 'buffer' to use on your night out. You'll only be taking in the same number of calories over the week that you would have done anyway, but in a different way.

We all know that for a lot of us, drinking alcohol can lead to bad choices. Here are a few tips so that those choices don't lead to ruining the progress you have made throughout the week:

- **Choose a lower calorie drink. Have a gin and slimline tonic rather than a fruity gin and lemonade. Instead of a Stella have a Coors Light, and just say no to Pina Coladas!**
- **Don't drink too quickly! Enjoy your drink, there's no need to rush or compete.**
- **As much as you may overindulge slightly with your caloric intake due to the drinks, it's the food choices that prove most detrimental – do you really need a full pizza to yourself?**
- **Be careful the morning after! You'll crave carbs, McDonalds and last night's pizza, but what your body actually needs is hydration, electrolytes and protein. Water, milk and chicken are your friend.**

FUNDRAISING focus

Central Line Superheroes

A group of ten superheroes walked the length of London's Central Line in a day to support Kinari Mehta, who has PH. Over £4,000 was raised for the PHA UK. Kinari said: *"I am amazed at the total amount raised. This all could not have been achieved without each and every donation, and all the beautiful messages of support along the way."* Asha Muhabir, one of the walkers, said: *"We are all sore, but we are so happy that we raised so much more than we ever thought was achievable. Thank you to all the people we met along the way for joining us on our journey and for your donations and kind words to keep us walking on!"*

Fundraising fitness class

Simmone Shearn from Dorset organised a fundraising fitness class in memory of her mum, who had PH. £693 was raised for the PHA UK. Simmone said: *"Mum was a dedicated nurse and I feel so strongly that PH needs to be brought to the fore. I feel devastated that she is no longer with us but want something positive to come out of it in her loving memory. The day was a big success and I'm pleased to do my little bit to contribute towards a great cause."*

Will walks the Thames

Will Perry completed the Thames Path Challenge, walking 100k in 31 hours to raise over £800 for the PHA UK after he had a pulmonary endarterectomy in January 2018. Will said: *"I did the challenge on my own, but it never felt like that because people were constantly cheering me on, and I was lucky to have my family there at all the major rest stops. I know I am incredibly lucky to have had the surgery and I have my life back. I just hope I can show people there is a life after PH."*

Village tea towels

Mary Jane Lomer raised £300 for the PHA UK by producing tea towels which map out the meeting places where she lives. The towel includes drawings of local pubs, shops, churches and cafes. Mary Jane, from Rowlands Castle in Hampshire, said: *"The idea for the tea towel design came to me when walking down The Green where I live, listening to groups of people chatting. It has been sold at Home Hardware and The Bumblebee Café in the village and proved extremely popular."*

(Irish) coffee and cake for Alana

A group of friends and relatives organised a cake and coffee morning in memory of Alana Smyth, who had PH. The event took place in County Down, Northern Ireland, raising £6,000 for the PHA UK. Alana's lifelong friend Andrea Morrison, who helped to organise the event, said: *"Alana was a brave young woman who never let her health dampen her spirits. We just wanted to do something to keep her memory alive while raising essential funds for the PHA UK."*

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

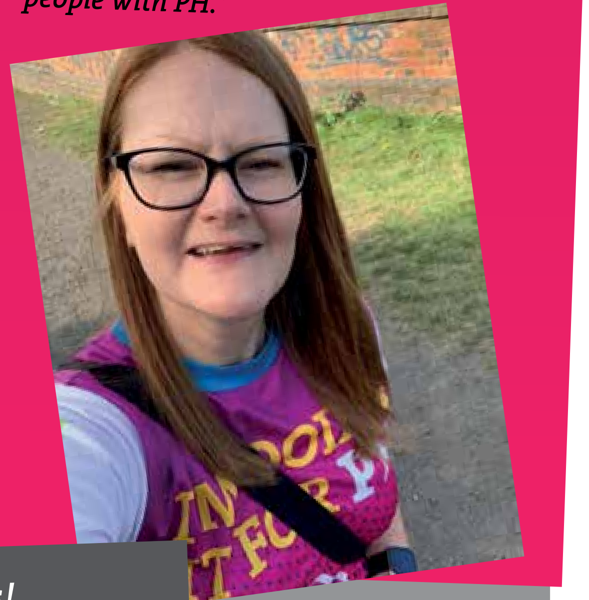
OUR GUIDE TO... VIRTUAL EVENTS

Do you want to fundraise for the PHA UK but can't commit to training for a big challenge? You could take on a 'virtual event', which is where you promise to walk, run or cycle a specific distance over one week, month or year. You can cover the distance at your own pace and wherever you want, making it easy to fit into your other commitments. Once you've completed the challenge, you receive a medal as a reward – and some organisers even offer clothing incentives too.

YOU CAN SET UP YOUR EVENT USING WEBSITES LIKE:

- **www.raceatyourpace.co.uk**
- **www.virtualracinguk.co.uk**
- **www.virtualrunneruk.com**
- **www.myvirtualmission.com**

PHA UK member Sharon Grainger completed a Race at your Pace walking challenge throughout September and has raised £35 so far. Sharon said: *"I originally set myself a 15k challenge but ended up doing more than 50k! I still have extreme fatigue and breathlessness so everything was very much at the pace I could go. But three years ago, this was something I never thought I'd be able to do, so I'm really chuffed that I've done it. I wanted to give something back as the PHA UK work tirelessly to help support people with PH."*



ME & MY JOB

This issue meet **Pamela Chikwa**, clinical nurse specialist at the Sheffield Pulmonary Vascular Disease Unit.

WHAT DOES YOUR JOB INVOLVE? As a clinical nurse specialist, we are the link between the medical staff and the patients. My work therefore involves following up patients by reviewing their clinical needs, making treatment adjustments and training patients in use of complex therapies such as administration of drugs via Hickman lines. We also generate fit to fly letters, prescribe oxygen therapy and plan for procedures like right heart catheterisation. I used to be a ward nurse and I made the jump to this role two years ago.

WHAT'S THE BEST THING ABOUT YOUR JOB?
I like the autonomy this role carries with it. As an independent practitioner I am able to make decisions about patient care by adjusting their therapies, giving advice and liaising with other multi-disciplinary team members. It is also great to be the first point of contact by patients whenever they call needing help.

WHAT'S THE FIRST THING YOU DO WHEN YOU GET TO WORK?
We have a telephone line which is open 24 hours, so the first thing I do is check the diary to see what out-of-hours phone calls we have had and follow them up in order of priority. We receive up to 20 phone calls out-of-hours each day.

WHAT DO YOU LIKE TO DO OUTSIDE OF WORK?
I have three sons, so I spend most of my time mothering them! I also like cooking, and I enjoy singing in my local church choir. I am currently doing a Master's degree in nursing so at the moment I spend most of my evenings studying.

CAN YOU TELL US AN INTERESTING FACT ABOUT YOURSELF?
Anybody who knows me will say that I absolutely love to laugh! When you do a job like mine and you are dealing with very poorly people, I think it's important that you find the time to have a good laugh. It's the first thing I do when I wake up and the last thing I do before I go to bed!

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

"It's been quite a year"

Richard Kitchener will always remember 2019 as the year he was diagnosed with Chronic Thromoboembolic Pulmonary Hypertension (CTEPH) and had life-changing surgery to give him his future. Here, the 52-year-old from Shepshed near Loughborough looks back on his journey.

Richard in hospital

Richard with his wife Sue

Richard regularly cycled 50 miles before his symptoms began

“My official diagnosis came at the start of 2019, but the symptoms began a long time before that. I'm a gardener, and it was when work began picking up again after the winter season that I began to feel lethargic and breathless.

I was always physically fit - I would regularly go out on my bike for 50 miles - and I just knew something wasn't right.

My doctor told me I had hay fever, even though I'd never had it in my life. I was coughing too, and I ended up having my lungs x-rayed, but they came back clear.

I struggled on through the summer and when autumn came, hay fever season went – but the symptoms were getting worse. Another trip to the doctors resulted in an asthma diagnosis and an inhaler.

I went back again, and my GP said he didn't know what to do with me, as I was a fit person, and all the tests were coming back clear. He asked me what I felt like, and I said I felt like I was dying.

He decided the next step should be a heart scan, and I was told it would be a wait of six to seven weeks. However, the day after, I had a call telling me there was a cancellation and the very next day, just 48 hours after the referral, I went to the hospital for what I thought was a routine appointment.

The scan revealed the right side of my heart was twice the size it should be, and I was admitted straight away. A CT scan showed multiple blood clots and I was told by the consultant that it was so serious that I shouldn't have walked into the hospital - in fact, I shouldn't still be alive.

I stayed in my local hospital on blood thinners and a few weeks later I was seen at Papworth. After various tests, I was told there was good news – the type of pulmonary hypertension I had was called CTEPH, and it could be treated.

When the operation was mentioned, I knew straight away it was what I wanted to do. I didn't feel like there was any other option.

On 25th September this year, I had a pulmonary endarterectomy which removed all of the clots and I am making a full recovery.

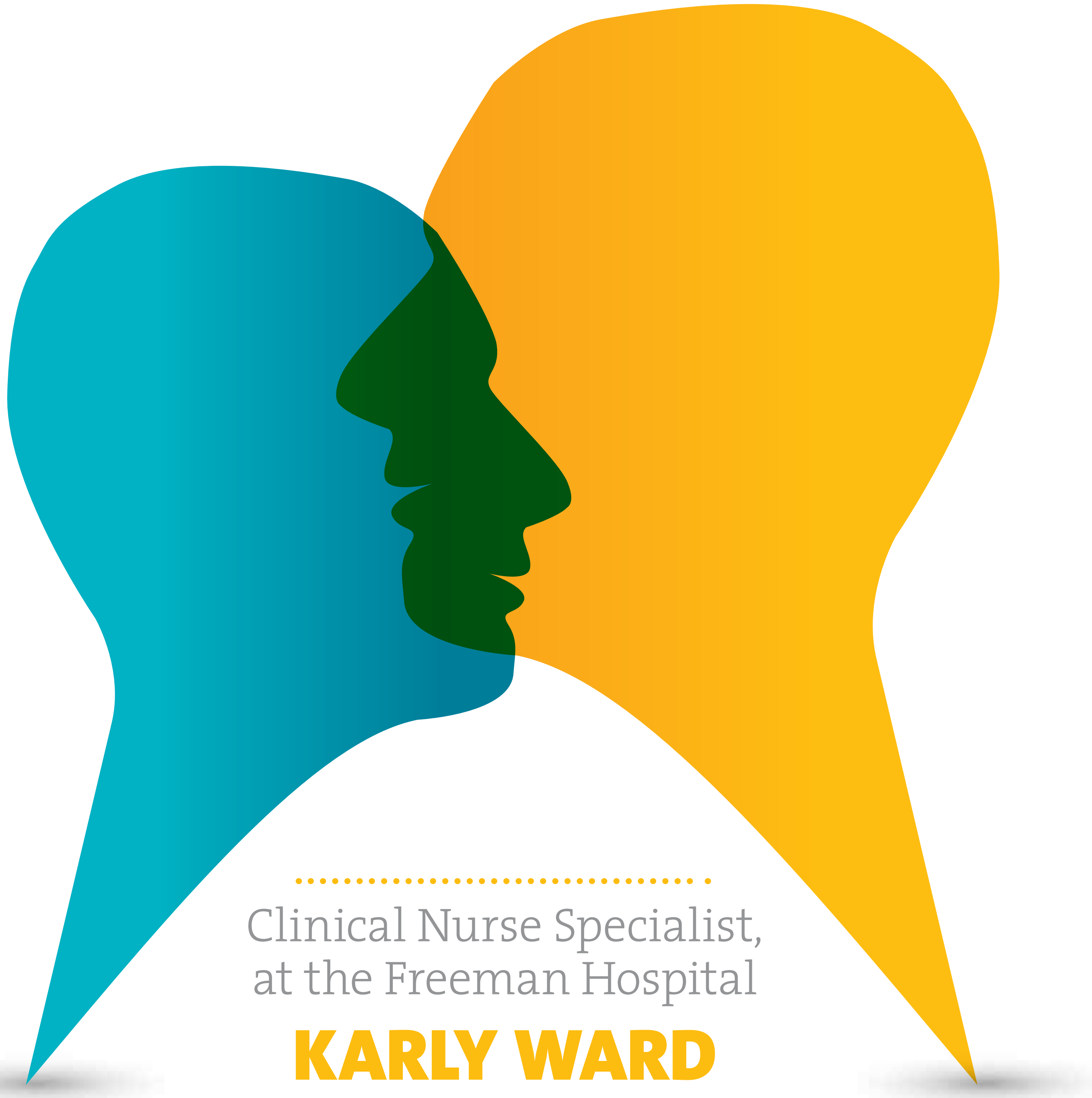
I do often wonder how different things may have been had I not got the cancellation appointment for the heart scan.

It's been quite a year, but it's onwards and upwards now and as a family we're all looking to the future.”

SUE'S VIEW

Sue Kitchener, Richard's wife, said: "It was a relief to finally get a diagnosis as we knew it wasn't hay fever or asthma, but you can't force the doctors to tell you what it is if they don't know. It was a rollercoaster after the heart scan, but we just had to get on with it. **And once we were under the care of Papworth we knew we were in the best hands. Now Richard's had the operation and it all went well, we feel like we can look forward, after putting our lives on hold for the last year."**

the*interview*



Clinical Nurse Specialist, at the Freeman Hospital

KARLY WARD

in conversation with

Chris Coates

Karly Ward is a clinical nurse specialist in pulmonary hypertension at the Freeman Hospital in Newcastle. She grew up in the small town of Newcastle (yes, really!) in County Down, before moving across the Irish Sea to study nursing at Northumbria University.

After qualifying in 2016, her first role was a ward nurse in the respiratory medical ward at the Freeman, where she looked after people with PH. Karly became a clinical nurse specialist in pulmonary hypertension in early 2018.

Q. As a child, what did you want to do when you grew up?
A. *From a young age I wanted to be a vet because I love animals. When you're young and naive you think a job where you can play with animals all day is going to be great! But I've always wanted to be in a caring role where I can help people. When I was doing my A-levels I did some work experience in a hospital and I spent time with physiotherapists, midwives and nurses - from that point I realised I definitely wanted to go into nursing.*

Q. What made you want to work in the field of PH?
A. *In my first role as a ward nurse I was interested in the pulmonary hypertension patients from an early stage. I spent a lot of time with Rachel Crackett, one of the nurse specialists in PH, when she was seeing the PH patients and carrying out investigations. The more I learned about the work the nurse specialists did with the PH patients, the more it excited me and that's what led me to apply for the job of clinical nurse specialist. Working with people with pulmonary hypertension means you see them regularly and I like that – you get to keep up to speed with how they're getting on. It's nice to see the change in patients as they go through the various stages of their treatment.*

Q. What are the challenges of living with PH compared to other respiratory diseases?
A. *I think the first challenge for patients is that they get passed between different specialists based on their symptoms, which can be really frustrating for them. When they do get the diagnosis, it's important to remember that it not only affects their physical health, but their emotional wellbeing is also affected. They have to adapt the way they're used to living and that can be hugely challenging – even something as simple as making a bed becomes so much more difficult. The second challenge is that PH is a hidden disease. I hear people's frustrations time and time again because they get told that they look so well, but obviously they don't feel well. It's important to realise it's not always something visible which could be affecting someone's health and wellbeing. I think that's one of the biggest things I've learnt from doing this job – there could be so many other things going on which aren't visible from the outside.*

Q. What is the most rewarding thing about your job?
A. *I love it when patients tell you that they feel so much better after talking to you. When we diagnose people with PH and tell them that there's no cure, it's quite daunting for them so...*

>>>

the*interview*

Clinical Nurse Specialist

KARLY WARD

> *“It’s important to realise it’s not always something visible which could be affecting someone’s health and wellbeing.”*

…I think a big part of our role as specialists is to listen to them and offer advice. Patients often confide in us and want to talk about issues that aren’t directly related to PH but they just feel like they have to offload. We give patients medication and hope it will improve their quality of life, but many of the issues can be resolved just by talking it through face-to-face or over the phone. They’re going through major life events and you’re there with them to guide them through.

Q. What achievement are you most proud of?

A. *My biggest achievement so far is getting this job! When I initially applied for it, I was advised that I might struggle because I hadn’t been qualified for very long and I was running before I could walk. But I decided there was nothing to lose and a lot to gain. I worked hard for it and I was proud of myself when I managed to get the job. I’ve really enjoyed my time so far and I hope there are many more enjoyable years to come working within the PH service.*

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

A. *Normally I start by checking my emails and the answerphone to see if we’ve had any messages. We usually have a lot of phone calls and appointments to make so we’re very reliant on our secretary to help us!*

I then catch up with my colleagues to find out what’s been going on. We take it in turns to be the nurse that covers the ward, so if it’s my turn to do that, I go around with the consultants and check on the patients which are on the ward. I check to see if anything needs to be organised for them or if there are any investigations which need to be followed up.

If it’s a clinic day, I get the chance to meet any new patients who have been admitted to the PH service. I introduce myself and some of the other doctors I work with, and then I like to find out a little bit about them and give them some information about what will be happening going forward. That also gives them the opportunity to ask me about anything that might be worrying them. Aside from that, I co-ordinate things like which patients are going to be seen by each doctor, and I also like to catch up with patients who come in for check-ups and see how they’re getting on.

Q. Who inspired you in your work?

A. *It may sound clichéd, but every person that I’ve worked alongside through my nursing career has inspired me. We’re so lucky to have amazing staff in the Freeman Hospital and the NHS in general. Like anyone, I have good days and bad days, but I’ve always been well supported and there’s always someone there for a shoulder to cry on or to have a laugh with. I spend more time with my colleagues than my family, so you become really close and you learn from each other.*

Outside of work, my mum inspires me the most. We speak every day on the phone, and I can honestly say that I wouldn’t be where I am today without her support and constant life advice! She’s always believed in me and encouraged me to do things that are out of my comfort zone so she’s very special to me.

Q. What’s the best piece of advice you’ve ever been given?

A. *I was once told to never have any regrets about what decisions I make in life. On a personal level, the advice I’ve given myself is to always start the day on a positive note.*

Q. What do you enjoy doing outside of work?

A. *I work a lot, so I don’t get much time off! But when I’m not working, my favourite thing to do is go back to Northern Ireland to see my family and friends. It’s my favourite place in the world so I do that as much as I can. When I’m in Newcastle (the English one!), I like to keep fit by going to the gym and get out and about to see new places. In the six years I’ve been here it’s quite bad that I haven’t travelled around the North-East to see what it has to offer but it’s definitely on my to-do list.*

I also like to go on a spa day or even just relaxing at home is enough for me. ●

www.phocuson**lifestyle**.org

Our sister website **to help you live well with pulmonary hypertension**

Our online resource is designed to support you with all aspects of life with PH.

- Relationships
- Exercise and nutrition
- Complementary therapy
- Mental and emotional wellbeing
- Travelling with PH
- Welfare and benefits

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REGULARLY UPDATED!

This is the site you’ll want to return to time and again for information, guidance and inspiration.

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, plus an app to help you keep calm.

Winter reading to keep you mobile and well-nourished

Sod Sitting Get Moving! by Diana Moran & Muir Gray
Sod it! Eat well! by Anita Bean & Sir Muir Gray

In these days of digital books and YouTube videos, it's refreshing to come across a couple of hard back staples that could become life-companions. And if you can get past the somewhat controversial 'Sod it...' titles, you may enjoy and benefit from the concentrated wisdom inside their covers. ***Sod it! Eat well!*** *and* ***Sod Sitting Get Moving!*** *are twin publications to set you up for the winter. Written in a relaxed and chatty style, they give good advice to the elderly (of which I am one!) on lifestyle and getting the best out of our later years. These are books that we can dip into as and when; especially the one on exercise.*

Sod Sitting Get Moving! provides illustrations of easy to follow and varied exercises. Also, the print's quite large and therefore readable even if you don't have your spectacles to hand. I tried all the exercises and found them well within my capacity, notwithstanding my elderly status and having had PH for over five years.

Sod it! Eat well! is more exacting, going into a level of detail that may make some of us glaze over, so skip those technical bits and go for the recipes, and such sections as 'How much fibre should you eat?' and 'Ten healthy snacks'. The recipe section offers a variety of healthy dishes, ranging from vegan to carnivore with such items as Chicken Tagine and Tofu and Red Pepper Stir Fry.

Each section has a helpful summary that saves making notes and that helps those of us whose short-term memory function is fading.

Co-written by Diana Moran, alias 'Green Goddess' fitness expert of the eighties; and Sir Muir Grey, knighted for services to the NHS as Chief Knowledge Officer, this combination of practitioner and theorist works well in providing exercises backed up by reasons why they should be beneficial to us. The appropriately named Anita Bean is a top nutritionist whose knowledge and experience underpins the advice and recipes in 'Eat Well'.

Reviewed by PHA UK member Heather Pollitt

Keeping 'Calm' app

You can't ignore anxiety. Having trouble relaxing and / or sleeping? I have found the Calm app exceedingly user-friendly and genuinely calming. As well as 'Daily Calm' sessions you can pick tracks to help you focus, relax or sleep. If you would like something a little different such as a 'Calm Body' there is a series of ten-minute guided videos on mindful movement.

I particularly enjoy the sleep stories designed to help you nod off. Nine times out of ten I am asleep before the story has finished. Many are read by well-known people who have extremely soothing voices, pitched just right to lead you into a relaxing sleep. There is something rather nostalgic about being read a bedtime story! My favourites so far have been the nature stories from around the world and surprisingly, the children's stories like The Velveteen Rabbit. There are stories to suit everybody.

You can download the app and sign up for a week's trial. Thereafter, the annual subscription is £35.99 (just under £3 a month).

Reviewed by PHA UK co-founder Kay Yeowart

Standing up for the PH community

At the PHA UK we're committed to fighting your corner, and we're not afraid to hold organisations to account if we have reason to believe they are not acting in your best interests.

When we discovered that the Stayveer® brand of bosentan will be withdrawn from the UK clinical market, we challenged the decision on your behalf.

We wrote to manufacturers Actelion (part of the Janssen Pharmaceutical Companies of Johnson & Johnson) who cited 'commercial reasons' for discontinuing supply of the pulmonary hypertension drug from December 2019.

We made clear our disappointment that, as a patient organisation, we were not consulted on the matter. If we had been made aware, we would have told them that the continuity of supply of Stayveer® has been of great value to patients transitioning from Tracleer® bosentan, and that there are a significant number of patients still very stable and doing well on the drug.

We have also learnt that the decision to withdraw was not discussed with specialist centres.

Following an unsatisfactory reply to our letter, we requested a telephone conference with senior representatives from Actelion, where we expressed our view that they are putting profits ahead of patients.

Iain Armstrong, Chair of the PHA UK said: *"It would appear from our communications with Actelion that the decision has been made because the drug does not carry enough profit, so efforts are being concentrated on different therapies. This is disappointing and contradictory coming from an organisation that has historically demonstrated commitment to patients. For many years, we have worked in collaboration with this organisation; most recently to help secure access to a new treatment for patients in the UK. I'm therefore also extremely disappointed they chose not to consult with ourselves, or the specialist centres, about the decision to withdraw Stayveer®."*

Although we were unable to reverse Actelion's decision to withdraw Stayveer®, we have succeeded in helping them understand the potential consequences to patients – and the benefits of consulting with us over future decisions.

We gave Actelion the opportunity to talk directly to patients via this magazine.

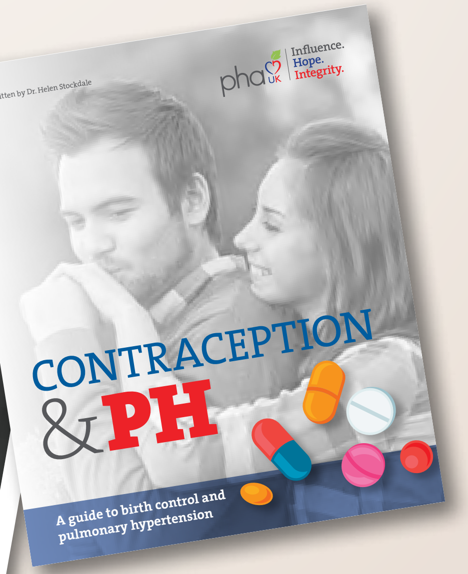
Jennifer Lee, Director of Access and Advocacy, said: *"The well-being of patients is our first priority at Actelion. We recognise that for some patients the decision to withdraw Stayveer®(bosentan) will be distressing and we do not take such decisions lightly. Patients and clinicians should be assured that there are currently several alternative treatment options available. Actelion remains committed to continuing our work with the UK pulmonary hypertension community and to improving the lives of people affected by PAH."*

Please be assured that if you are currently taking Stayveer®, your specialist centre will work with you to safely transition you onto a different brand before supplies of Stayveer® come to an end. We have been reassured by Actelion that there is a 'significant' remaining stock of Stayveer® so we urge you not to panic. ●

If you have any concerns about switching between different bosentan brands, please contact your specialist centre.

Contraception and pulmonary hypertension

Consultant pharmacist *Neil Hamilton* looks at what you need to consider when making decisions about birth control.



Written by Dr. Helen Stockdale

CONTRACEPTION & PH

A guide to birth control and pulmonary hypertension

Recently, I was honoured to be asked for my input into the PHA UK's latest publication, *'Contraception & PH – a guide to birth control and pulmonary hypertension'.*

We should all be aware of the significant risks faced by patients if they become pregnant. As such, contraception is vitally important for any woman of childbearing potential. The book goes into great detail in describing the range of birth control measures currently available. It talks in depth about likely success rates and the reasons why these may fail.

In the course of this article, I thought it would be helpful to run through some key points from the book. I thought this would be useful for those of you who may not read the full book.

Drug interactions

'Interaction' is the special term given to the effect one drug / medicine has on another. Lots of drugs interact with each other and one of our PH treatments, bosentan, has a number of interactions. In this context, bosentan can interfere with some contraceptives, causing them to be less effective. Anyone taking bosentan may need higher doses or additional forms of contraception to prevent an unwanted pregnancy. Therefore, if you are taking bosentan and need contraception, make sure the prescriber is aware so the doses can be adjusted appropriately.

Ideal vs. typical use

The book explains the interesting contrast between the likely effectiveness of all the different contraceptive methods in terms of ideal and typical use. When I read the statistics, I was struck by the big difference between a method's protection when used in an 'ideal' way compared to average or typical use. Probably the best example is the male condom; very reliable when used ideally, but because of the potential problems such as leakage or splitting, its typical use cannot be totally relied upon.

A range of options

Choice of contraception is a very personal one. There is a wide range of options currently available. Each has its own pros and cons and the book goes through each of these to help patients make an informed choice with the best evidence and information available. As always, each patient must make the final decision as to which suits their own circumstances best. The book is there to aid that process. As with the recently published PH medications book, we have included a number of conversation starters. These are meant to act as thought-provoking questions that get you thinking. They represent the most common questions asked in the clinic, which may be at the PH centre, GP surgery or family planning centre.

Contraceptive pill

The most commonly prescribed pills are the 'combined oral contraceptive pill (COCP)'. These are a combination of two different hormones; oestrogen and progesterone. These are not recommended in PH due to the oestrogen component. Oestrogen increases the risk (albeit very slightly) of blood clots. As such, the contraceptive pill recommended in PH is the progesterone-only pill, sometimes called the mini-pill.

Emergency contraception

The final section in the book covers the 'if all else fails' scenario. Despite best-laid plans things can still go wrong, or at least you may be anxious that they have. The most common emergency contraception, the oral emergency contraceptive (sometimes called the morning after pill) can be taken up to 72 hours (three days) after unprotected sex. Some people may not be aware that these are available from your local pharmacy. Pharmacies are likely to be more accessible than a GP appointment, especially out of hours or at the weekend.

As a slight aside from topics in the book, I'll finish with some discussion about medication and pregnancy. Whilst the team at your specialist centre will have discussed the risks to the mother in pursuing a pregnancy, many people are not aware that many common medicines can be harmful to the unborn baby. The list includes but is not limited to; ACE inhibitors such as ramipril, some anti-epilepsy medicines, some antibiotics, some anti-cancer medicines and some thyroid medicines. In addition, there are some other medicines even more likely to be prescribed to patients with PH, such as warfarin and Endothelin Receptor Antagonists (Ambrisentan, Bosentan and Macitentan).

In the regular blood tests done for the Endothelin Receptor Antagonists, we undertake a pregnancy test to check, but the for the other medicines listed above there is no such 'safety net'. Therefore, I advise anyone seriously considering becoming pregnant, or who thinks they may already have conceived, to contact whoever prescribes their PH medication so any necessary changes can be made as soon as possible.

As always, the team at your PH centre are on hand to answer any questions that you may have regarding contraception and risks of pregnancy,

but the team at the PHA UK have put together a resource here which will doubtless be of great value. The PHA UK resource centre has taken delivery of the first print run and has already sent some out to the specialist centres. **If you are interested and are not due in clinic anytime soon, you can contact Shaun, Helen and the team and they will be very happy to send you a copy. You can also order online at www.phauk.org**

A series of videos to accompany the printed resource can be found at ***www.phocusonlifestyle.org*** Just type *'contraception'* into the search bar.

Reducing loneliness *this Christmas*

During the winter months, some older people may experience loneliness and feel isolated. We take a look at some of the free services available which can provide friendship and hope this Christmas.

Contact your local Age UK to find out about their befriending service

Call in Time is Age UK's national befriending service where a volunteer befriender will call an older person at an agreed time for a chat. The charity also provides a face-to-face service.

Call the Age UK Advice Line on 0800 678 1602

The Age UK Advice Line is a free, confidential, national phone service for older people, their families, friends, carers and professionals, which is open 365 days a year (8am-7pm).

Call the Silver Line Helpline on 0800 470 80 90

The Silver Line is a dedicated helpline open 24 hours a day which provides support to people who are suffering with loneliness in the UK, particularly those in their 70s and older.

Spot the differences!

Did you find all 6 things which didn't match? Here's the answers...

In your Spring 2020 issue of Emphasis...

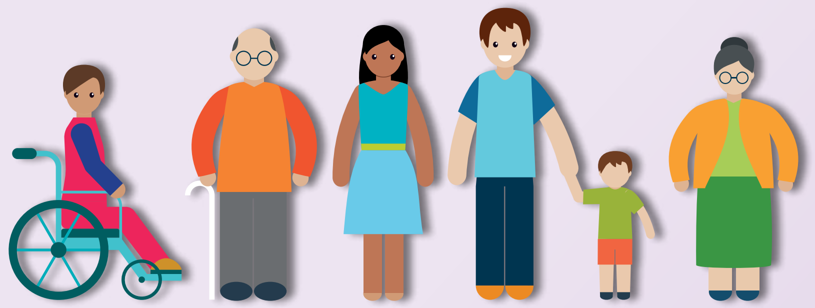
The next issue of Emphasis is due out in March and planned content includes:

Internet dating
A guide to finding love online

The different types of PH
A closer look at the variations of the disease

Weight loss tools
Helping you reach the right weight for you

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



Join our PH family for free today

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Influence.
Hope.
Integrity.

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

Being part of the 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.

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*

YES! I'd like to join the 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
How we're structured

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

STRATEGIC PARTNERSHIPS
Anxiety UK
Turn2us

EXECUTIVE TRUSTEES
Iain Armstrong
Chairman
Kay Yeowart MBE
Secretary
Tom Siddons
Treasurer

TRUSTEES
Sue Townsley
Tracie Parnell

OTHER CHARITIES
(National & International)
Collaborative working and learning

CORE STAFF
Shaun Clayton
Director of Membership Support
Helen Crabtree
Senior Office Administrator
Iain Armstrong
Chairman
Paul Sephton
Research Support & Development Coordinator

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

PHA UK Contact Details

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

Anxiety UK

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

Turn2us

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

Do we have your correct details?

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

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

Free PHA UK publications for support and advice

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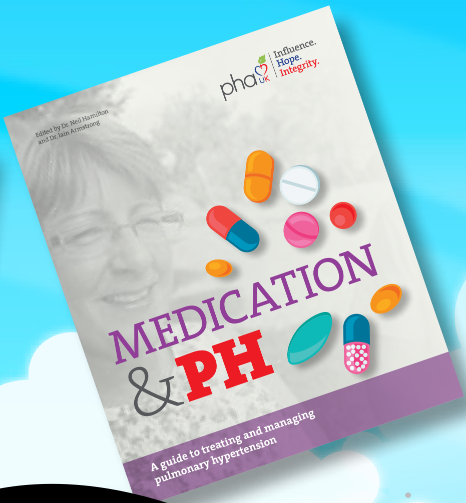

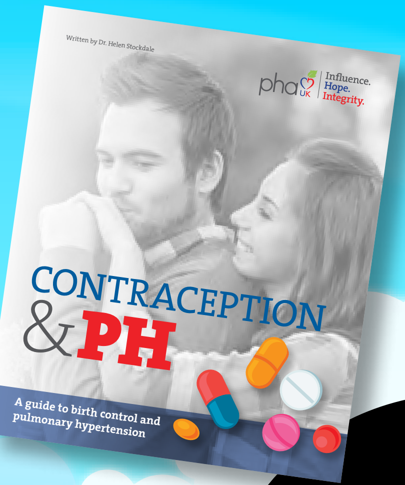

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