SPRING 2018

emphasis

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

Mental health

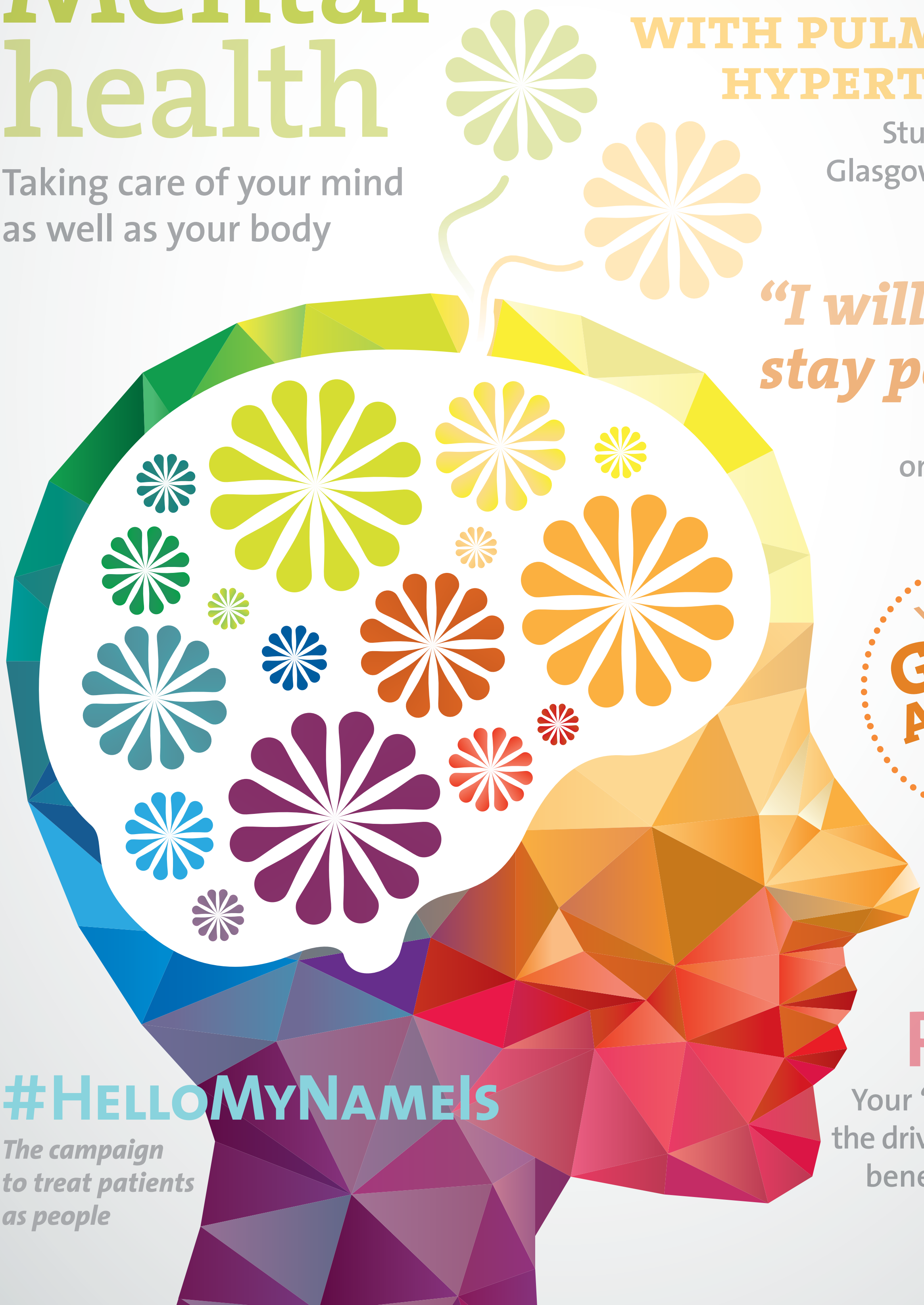
Taking care of your mind as well as your body

KEEPING ACTIVE WITH PULMONARY HYPERTENSION

Study results from Glasgow and Sheffield

"I will always stay positive"

Tess looks back on 10 years of PH



YOUR GOLD AWARD WINNING MAGAZINE

SEE INSIDE FOR DETAILS!

#HELLOMYNAMEIS

The campaign to treat patients as people

PLUS...

Your 'happy' photos, the drive for Selexipag, benefits advice and much more!

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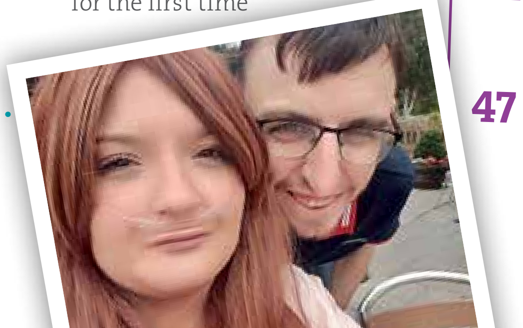

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This magazine is printed on paper from sustainably managed sources

Could you support us by playing our *PHA UK Lottery?*

At PHA UK we rely on our supporters to continue our mission to improve the lives of people with PH. Playing the PHA UK Lottery is a fantastic way to support our work through a small regular donation.

Iain Armstrong, Chair of PHA UK, said: *"It's free to join PHA UK so our Lottery is a great way for supporters to contribute a little money on a regular basis to support the charity's work. We need to raise money to fund better treatment plus support PH patients and their families and every little helps."*

For just £1 a week, you can play the fundraising PHA UK Lottery.

So how does it work? Each week PHA UK Lottery players are allocated a six-digit number and the winning numbers are selected every Saturday. Cheques are then posted to winners directly – there's no need to check your numbers or make a claim yourself.

- **Match six digits to win £25,000**
- **Match five digits to win £1,000**
- **Match four digits to win £25**
- **Match three digits to win £5**

You can increase your chances of winning by purchasing more than one entry.

Signing up is simple!

Go to either **www.phauk.org** and search *'Lottery'*, or **www.unitylottery.co.uk** and search *'Pulmonary Hypertension Association UK'* or complete the form attached to the Leaflet enclosed with this magazine.

> *"It's nice to support the PHA UK with a regular donation, with the added bonus of maybe winning a prize."*
> **Sarah, Oxfordshire**

> *"I play because I like to know the money is going to a charity that's close to my heart... and to my lungs!"*
> **Darren, Glasgow**

> *"I play the PHA UK Lottery to support the charity in their research. Plus, I've won some money a couple of times too!"*
> **Catherine, Lancashire**

Welcome

CIPR PRIDE AWARDS 2017 GOLD WINNER

Welcome to your award-winning magazine! We were delighted when, just before Christmas, Emphasis was named 'Best Publication' at the prestigious Chartered Institute of Public Relations awards.

We'd like to thank everyone who shares their news, views and experiences to help make the magazine what it is. The award is something we can all be proud of together.

This issue of Emphasis focuses on mental health, and how looking after it is integral to our wellbeing. On page 20, Philippa Horn offers a unique perspective as a psychological wellbeing practitioner who lives with PH herself. Mental health issues can affect children as well as adults and on page 47, eleven-year-old Darragh shares how therapy helps him cope with his long-term health condition.

Don't forget that our partnership with Anxiety UK gives all PHA UK members free access to a dedicated phone and email support service, or help and advice around any issue relating to anxiety and depression. Turn to page 46 for details.

If you need a little lift, take a look at the photos on page 16. Earlier in the year, we asked you send us the snaps that make you feel happy and we were overwhelmed by the response. We hope you enjoy looking at them as much as we did.

Someone who believes in the power of positivity is member Tess Jewson, who this year celebrates a decade since her diagnosis. She looks back on her journey on page 22.

Finally, do take a look at the report that was mailed with this magazine. The National Audit of Pulmonary Hypertension takes place every year and it's really encouraging to see how well the specialist centres in the UK are performing. We have a network of care in this country that we can really be proud of.

Iain Armstrong

Iain Armstrong
Chair of PHA UK
editor@phauk.org

> *"The award is something we can all be proud of together."*

Emphasis *exchange*

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

DEAR EMPHASIS,

Chesterwood Show, now in its thirteenth year, was as successful as ever, raising £1,459.30 for the PHA UK.

We had entries in each of the show jumping, 'handy pony' and games classes, with lots of younger children taking part this year, which was great to see.

Jackie and Josie Brown again very kindly donated a handmade jump to the show. They gave it to the person who they thought most deserved it, someone whose riding improved most over the course of the day. The very lucky recipients this year were sisters Hannah and Faith Rourke.

Thank you very much to all the sponsors and helpers without whom the show couldn't go ahead. A special mention must go to Jools Howard from High Plains who again generously donated some Woodland Ride vouchers.

A massive thank you must also go to my sister Suzie Pigg for organising the show; she has done this for the past thirteen years and has made it into the success it is today. Thanks also to Graeme for allowing us on his land and Brenda, Ellen and their team for the gorgeous food.

We had an amazing day and raised the fantastic sum of £1,459.30 which is brilliant. This, together with previous years, means we have raised an amazing £19,220.27.

These contributions and the show itself help enormously towards raising awareness of pulmonary hypertension.

Many thanks again to you all.

SHEENA ROBINSON

NATIONAL INSTITUTE FOR HEALTH RESEARCH RECOGNISE EXERCISE THERAPY FOR PH PATIENTS

The National Institute for Health Research (NIHR) has announced its intention to fund research into exercise and physiotherapy for people with PH in the UK. Following this announcement, clinicians from all of the specialist PH centres met in February to discuss a joint bid. If successful, the team could start research as early as 2019.

Dr Martin Johnson at the Scottish Pulmonary Vascular Unit (SPVU), who is leading the bid, said: *"The recognition of exercise therapy by the NIHR and NHS is extremely encouraging and we anticipate bigger studies over the next few years."*

*See more on exercise programmes on **page 28**.*

New data protection regulations

New data protection legislation, known as the General Data Protection Regulation (GDPR), will come into force in May. We want to take this opportunity to remind you that at the PHA UK we take your personal data and your privacy very seriously.

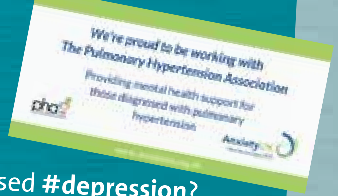
You can trust us not to sell, share or pass on your personal details. We think of the PHA UK as a family, built on trust and respect - and for that reason, your data will always be safe with us. ***That's a promise!***

Social Media Round-up

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

@sallybtipper
Huge, huge congratulations to Phil and all the others who conquered **@TheSpineRace**. An incredible achievement and much-needed funds raised for a cause close to lots of our hearts **@PHA_UK**

@AnxietyUK
Are you a member of **@PHA_UK** looking for support with **#anxiety #stress** or **#anxiety** based **#depression**? Why not explore the support available through Anxiety UK!



We're proud to be working with
The Pulmonary Hypertension Association
Providing mental health support for those diagnosed with pulmonary hypertension

@maritess_mt
Ah it's arrived... snuggled up in the sofa bed with a Baileys hot chocolate & the **@PHA_UK** award winning emPHAsis magazine! **#snowday**

Chris Wiseman
First class support from PHA UK and always on the end of a phone. I'm 5 weeks post-surgery and recovering well and it is nice to know that a fabulous team is behind me

Pulmonary Hypertension Association UK
So pleased to announce that Emphasis - your member magazine, has won Best Publication at the CIPR PRide Awards! **#Gold**

Join us on Twitter at 1pm on 4th May for a live 'Twitter chat'. Use the hashtag #ActOnPAH to join the conversation!

Tom Jones.

Family produce music album to raise money and awareness

A family with first-hand experience of living with pulmonary hypertension have put together a unique music album to raise money for the PHA UK.

Brothers Tom and James Jones from Standish, Wigan have worked with their father Rob, who lives nearby, and a number of musicians to produce 'Old Wives' Tales'. It uses 12 tracks by different musicians, plus a medley and narration, to tell the story of a guitar over a 50-year period - based on the contributors' memories of how they first fell in love with music.

The album, which took 12 months to complete, has been produced in support of Tom and James's mother, Karen, who was diagnosed with PH in 2011. She also lives with systemic sclerosis.

Rob said: *"Although it is beneficial that the public are aware of, and contribute to research for a number of well known serious medical conditions, it became clear that other illnesses hardly exist in the public consciousness and struggle to attract funds - even though these same ailments take a shocking toll on the sufferers. This was our attempt to put PH in the spotlight a little and to raise some much-needed funds".*

Old Wives' Tales costs £5, with the money going directly to the PHA UK. It can be purchased and downloaded from **www.oldwivestales.bandcamp.com** and a promotional video can be viewed via the album's own Facebook page by searching 'Old Wives' Tales album'.

The family are hoping that in the future it can be performed as a concert, to raise even more money.

PH publications for FREE

We want to make it as easy as possible for people to access support and information about pulmonary hypertension, so we've made all our publications available to order for free online. Visit **www.phauk.org/publications** and choose from subjects including accessing benefits, managing breathlessness and talking to loved ones – plus much more.

My strength and support

After John Locke passed away last year, a memorial service and sponsored walk in his memory raised £2000 for the PHA UK. Here, his wife Sue remembers the life they shared.

"John was diagnosed with leukaemia 26 years ago. We thought things were going well, and we enjoyed holidays - mainly in our caravan, with the odd one abroad.

In 2002 John was diagnosed with Idiopathic Pulmonary Hypertension. Once we got to Papworth Hospital in the care of Joanna Pepke-Zaba and her team, we knew we were in good hands. Dr Jo was always so positive and pushed for John to be as well as she could make him.

John had tremendous strength and determination to live his life in full, never to let it get the better of him or stop him doing what he wanted, be it time with family or holidays. I feel this attitude contributed to the 15 good years we had as much as the medication.

In those 15 years we have had several holidays in Florida including our 25th wedding anniversary, a week in the theme parks and a week-long Caribbean cruise. We took all our family back to Florida two years ago, from which we both got tremendous pleasure with our grandsons' faces full of excitement (priceless). We continued to work to fund our holidays and to pack in as much as we could, while we could. We followed this up with two Mediterranean cruises and John's 60th in Rome. We even managed to climb the Parthenon, at our pace of course. Yes, we have spent a lot of money on holidays but our favourite sayings were 'no pockets in a shroud' and 'let's spend and enjoy it' – because of this I now have the most fantastic memories of all our lovely holidays.

John's strength and positive attitude has been what has got me and our family through these last difficult months. Yes we are sad at times and we do miss him dreadfully, but he will always be with us and continue to give us strength.

As a family we hope that even if only one person is helped through their difficult time by reading this article, it will bring us some comfort. Please stay positive, be determined to fulfil your dreams and enjoy your life to your limits."

Sue, Daniel, Maria, Henry, Archie, Matthew and Vivian

Branded clothing now available

PHA UK branded hoodies, sweatshirts, polos and t-shirts are now available to buy online at **www.phauk.org/shop**. Available in a wide range of colours, the clothing comes in a range of child and adult sizes too, and 30 per cent of each item sold goes to the PHA UK.

Did you know?...

60% of the rubbish that ends up in the dustbin could be recycled. So, if you've received this Emphasis magazine through your door, don't forget that **the wrapper it came in can be recycled.**

Save the date for **PH Week 2018**

This year, our PH Awareness Week will take place from ***22nd – 28th October***. Pop it in the diary and look out for ways to get involved later in the year.

PH AWARENESS WEEK 2018

Dear PHA UK

I am writing to you after sadly losing my Mam, Rose Kelly, in December last year. Mam was 83 years old and despite being diagnosed with PH in the March, she never complained once. She was the bravest and strongest person I have ever met.

She was on oxygen 24/7 but it didn't stop her from being cheerful and full of fun and mischief. She made the most of every day and would often have a tot of whisky before going to bed.

Mam was diagnosed as having advanced PH and was put on sildenafil to help open the blood vessels – she used to joke about selling them on the high street so we could have a holiday in Benidorm. Of course, she never did, but that was her mischievous sense of humour.

Throughout her illness she was cared for wonderfully by the PH team at the Freeman Hospital, and she got to know the specialist nurses very well.

Mam always said that when her time was up she didn't want us to mourn her passing but to celebrate her life because she had enjoyed life to the full. Both Mam and Dad had travelled all over, including Australia.

We had a donation box at Mam's service and are pleased to have raised £345 for the PHA UK. We know this will be used to help many others' who have PH and hopefully one day a cure will be found.

Thanks to everyone for the help and support given to Mam.

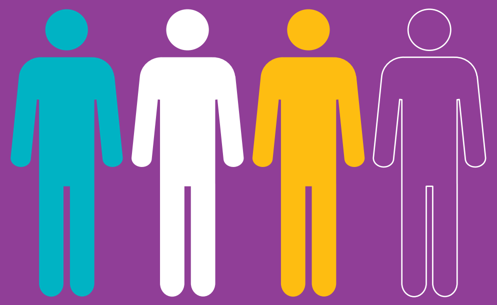
Kind regards

Eileen Kelly

Rose pictured with her husband Dominic.

NATIONAL REPORT SHOWS
PH centres exceeding targets

The UK's specialist PH centres are meeting more of the national standards set by the NHS, according to a new report into their performance.



The eighth National Audit of Pulmonary Hypertension, based on data gathered between 1st April 2016 and 31st March 2017, showed significantly more of the targets were met compared to the previous year.

For example, 98 per cent of patients referred to a specialist centre were seen, assessed and diagnosed within six months - exceeding the target by three per cent and showing a six per cent improvement. And the data showed that 96 per cent of patients had seen a specialist consultant at least once over the preceding 13 months; representing an improvement of four per cent and exceeding the target of 95 per cent.

The audit also showed improvement in many other areas, including the measurement of quality of life. The NHS standards set out that quality of life questionnaires should be recorded for patients at least once a year. The target set was 90 per cent and the centres hit 88 per cent – which is a 14 per cent increase on the previous audit period.

Plus, more patients than ever (91 per cent) received a right heart catheterisation before being diagnosed, representing an increase of three per cent. The target set was 95 per cent.

Iain Armstrong, Chair of the PHA UK, said: *"It's fantastic to see improvement in many areas, which is testament to the staff who work extremely hard in what we all know is a high-pressured NHS. It's also very encouraging to see that significantly more of the standards have been met compared to the previous year, cementing the UK's specialist centres as the envy of the world."*

The PHA UK played a vital role in setting up the National Audit of Pulmonary Hypertension by funding its first year in 2010. The audit is now funded via NHS Special Commissioning in England, and managed by NHS Digital (formerly The Health and Social Care Information Centre) in Leeds.

Other findings from the National Audit of Pulmonary Hypertension included:

87% of patients had a WHO functional class and six-minute walk or shuttle exercise test recorded before being given drugs to treat PH.

52% of patients referred to a specialist centre attended a consultation or were discharged within 30 days.

For **91%** of patients, their first line drug therapy was a phosphodiesterase 5 inhibitor.

THE NATIONAL AUDIT OF PULMONARY HYPERTENSION 2017
KEY FINDINGS

This is the eighth year that the UK's pulmonary hypertension services have been asked to provide data on what they do and what their outcomes are, and it's fantastic to see improvement in many areas. Congratulations to the staff who work extremely hard in what we all know is a high pressured NHS.

The National Audit of Pulmonary Hypertension is delivered by NHS Digital and commissioned by NHS England and measures the quality of care provided to people referred to PH services in England (including patients referred from Wales) and Scotland, by answering three key questions:

- ***Are pulmonary hypertension services appropriate?***
- ***Are patients receiving the right treatment in a timely manner?***
- ***What are the outcomes for patients with pulmonary hypertension?***

The audit answers these questions through the measurement of a number of professionally agreed targets reported at a national level, and covers the time period of 1st April 2016 – 31st March 2017. It's very encouraging to see that significantly more of the standards have been met compared to the previous year, cementing the UK's specialist centres as the ***envy of the world.***

For the second year, the PHA UK has taken the key findings of the report and presented them in a clear, accessible way. We've done this so you can see, at-a-glance, how the PH service in the UK is performing.

Once again, we're bringing you the information that's important to you, by including the statistics you told us you wanted to know about most.

As always, we'd love to know what you think about the findings of the National Audit of Pulmonary Hypertension and how we've presented them. Please email us at ***office@phauk.org****, call us on* ***01709 761450*** *or tweet us* ***@PHA_UK****.*

We hope you enjoy reading this report.

Iain Armstrong
Iain Armstrong
Chair of PHA UK

pha UK Influence. Hope. Integrity.

A summary of the findings from the National Audit of PH was mailed with this magazine. To see it online, visit www.phauk.org. To request a printed copy call 01709 761450 or email office@phauk.org

The full report can be viewed at www.content.digital.nhs.uk/ph

Making patient voices heard in the debate around Selexipag

PHocus2021 has been working hard to make patient voices heard in the drive for a newly licensed treatment to be made available to people with pulmonary hypertension (PH).

Selexipag helps to relax and widen the pulmonary arteries, relieving symptoms of PH and slowing down progression of the disease. It is taken as a tablet, providing an alternative for the first time to drugs usually only available intravenously or by inhalation.

Selexipag, also known as uptravi, has been licensed for use. However, the health agencies in England, Scotland and Wales - who are tasked by the devolved governments to recommend whether to fund newly-licensed drugs through the NHS - are yet to decide whether it will be made available. England and Wales have already reviewed this drug once and said no. This is being very strongly challenged and new processes have been restarted.

Part of the decision-making process involves the agencies consulting with clinicians and patient representatives, so PHocus2021 is working in collaboration to ensure the patient voice is heard loud and clear. It is essential that in making their decisions about whether to fund access to a treatment, these agencies understand what it is like to live with PH, and what impact a new treatment may have on patients' lives.

We've been submitting evidence, including the results of the recent Living with PH survey, responding to questionnaires and fighting to represent the PH community at agency meetings. We've had to be assertive, and it's not been easy at times, but we will continue until we get the outcome that patients and their kinship want and need.

In July, our open letter criticising the decision not to fund the drug in Scotland was published in influential newspaper The Sunday Herald. The Scottish Medicines Consortium are now reconsidering and we are also working in collaboration with the National Institute of Clinical Excellence (NICE) and All Wales Medicines Strategy Group (AWMSG) to help them understand why funding Selexipag is so vital.

Iain Armstrong, chair of the Pulmonary Hypertension Association (PHA UK) and co-chair of PHocus2021 said: *"As a PH community we don't ask for much; we just want the same equality and access to treatment as other disease areas like cancer. Selexipag is an important new drug and we know it is no more expensive than other alternatives. PH patients need access to the right treatment, at the right time. But despite the rhetoric of 'public engagement', even as a large patient organisation we have had to battle hard at times to even be invited to negotiations about its future. Making patient voices heard in this debate is as much of an issue as access to the drug itself.*

"PH patients may be ***breathless but they're not voiceless****, and we're working tirelessly to make them heard. The bigger our voice, and the more collaboratively we work, the better the outcome will be - for access to treatments, and much more besides."* **Watch this space!**

2021 PHocus

PHocus2021 is the advocacy programme established by the PHA UK to ensure pulmonary hypertension receives greater attention from Government.

Find out more at **www.PHocus2021.org**

Breathless, not voiceless.
It's time to turn up the volume for PH patients.

Our 4 aims for positive change...

PACING THE Pennines for PH

Phil Marshall recently completed a gruelling 268-mile run across the Pennine hills, raising over **£14,000** for the PHA UK in support of his wife Sarah. He spoke to Emphasis about battling extreme conditions for six days to make it to the finish line.

MONTANE SPINE

Sarah Marshall was diagnosed with PH in 2013 and since then, her husband has completed several challenges to raise money for the PHA UK. But not content with marathons and 100-mile runs, Phil decided to take on the most gruelling endurance race in the UK in a bid to top his previous achievements.

The Montane Spine Race takes place every January and is described as the most brutal race in Britain. It takes participants 268 miles non-stop across the Pennine Way through the Peak District, Yorkshire Dales and Cheviot Hills on some of the toughest terrain in the country.

Phil said: ***"I was running for 155 hours and only slept for one or two hours at a time as the race was non-stop."***

He also had to battle with the elements as strong winds, rain and blizzards swept across the Pennines. At one stage, conditions became so bad that the race had to be suspended for six hours on safety grounds.

"I've run across exposed mountains in Britain before, but the weather was the most extreme I've ever experienced. For the first few days the rain was constant, and then I had to deal with snow drifts which were waist-deep in places."

Exhaustion and sleep deprivation took their toll on Phil as the race went on. ***"I suffered from hallucinations of sofas and chairs in front of me which seemed so life-like. I also leant against a signpost which wasn't there and fell into a snowdrift.***

"I was forced to find farm buildings, phone boxes and public toilets to sleep in for a couple of hours and shelter out of the weather." Phil called Sarah at 5am one morning as he started to doubt whether he could complete the race. *"Sarah pushed me on and told me to just get to the next checkpoint. I don't think she got much sleep either because she spent most nights tracking where I was online."*

> *The weather was the most extreme I've ever experienced*

After almost a week of extreme weather, the morning of the final day was when Phil felt it was all worthwhile. ***"I'd climbed up the Cheviot Hills which was the last peak, the sun was coming up and there were only 20 miles to go. From that point, I knew I would make it."***

At the time of going to print, Phil's efforts have raised over £14,000 for the PHA UK. He added: *"I've been blown away by the generosity of people. I've been contacted by complete strangers pledging money and sending their support, which has been unbelievable.*

"Everyone has been so supportive and interested in Sarah's journey, which is what doing the run was all about – raising awareness.

"As fundraisers we're not researchers or medical professionals, but what we can do is raise money."

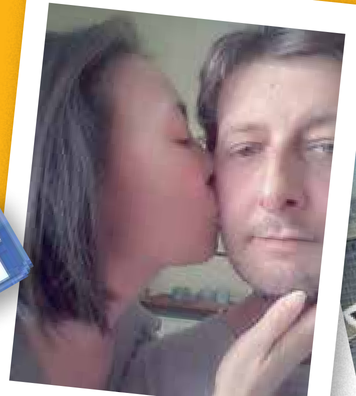
You can still sponsor Phil by visiting his Just Giving page at justgiving.com/fundraising/phil-marshall15

©No Limits Photography

The photos that make us smile

At the beginning of the year, we asked you to blow away the January blues by sharing your 'happy snaps' with us on Facebook. We were overwhelmed with the response, and couldn't resist printing some of them here.


Me 2/1/18 just post-catheter for PH! Finally getting some answers!
Elizabeth Hollingworth-Evans


My beautiful Amy
Bryan Lant


Happy family times. This was taken last Christmas, had a fantastic two days in London with my hubby and daughter xx
Sarah Louise Moxon


My little family xx
Lou Chadburn


These two give me the boost I need and can make me smile on a down day
Helen Akers


Xmas Day 2017. My motto in life is no matter how rough you feel, there is always time for a laugh.
Bev Brackenridge


Me with my brother and sister on her wedding day xx
Catherine Makin


Despite her PHight for every breath Haylee (diagnosed age 3) lives HAPPY
Nicole Phillips


Surfing with my beautiful daughters only 6 weeks after diagnosis!
Mike Peck


My gorgeous grandkids who keep me going even on hard days
Carol Childs


My three beautiful grandchildren are my reason to keep going!
Pam Ellis


My lovely niece Sarah and me, taken at my brothers 40th birthday party. She likes to check that my medicine is ok (my IV line)!
Gail Lanigan


My reason for fighting!
Jacque Wilkinson


When you can enjoy going out again with friends after PTE surgery
Sharon Emma


Tim Smith

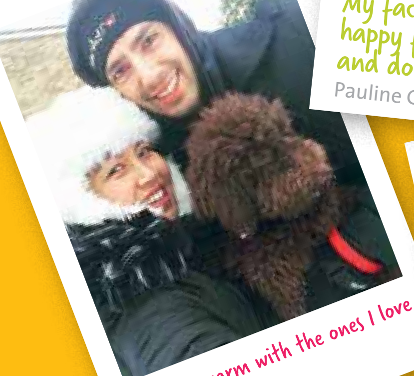

My baby girl was 2 days old here. She makes me get out of bed and make the most of every minute I have with her.
Leanne Michelle Hopkinson


My face with PH and my happy face after my heart and double lung transplant.
Pauline Ginn

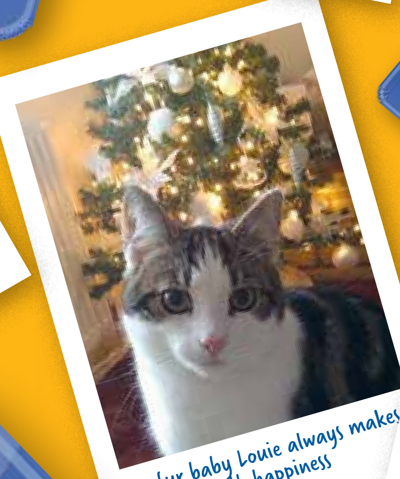

When you can get out with your family and enjoy life
Richard Annett


My beautiful daughter and grandson x
Marie Maynard


My daughter Molly, on left, with PH, spending time with her cousin Layla
Alice Taylor-Gee


Keeping warm with the ones I love
Tess Jewson


Christmas with some of my family x
Denise Smith


My fur baby Louie always makes me smile with happiness
Kim Langley


Me on the right before PH fully took hold.
Mark Kingston


Paula Dee


Skydive for PHA UK for my Nan!
Zara Louise Taylor


After four grown up grandsons came my long-awaited granddaughter...x x x
Jennifer Clarke

We love seeing your photos and hearing your news! Contact us at editor@phauk.org or on Twitter @PHA_UK and Facebook @PULHAUK

NEW!

AT-A-GLANCE GUIDES TO HELP YOU ACCESS FINANCIAL SUPPORT

Downloadable guides to help you get what you are entitled to are now available for free at **www.phauk.org**

A quick guide to...

What benefits are available

A brief overview of the different types of benefits that may be available to you, with links to find out more.

A quick guide to...

Important definitions

There are particular phrases that the Department of Work and Pensions (DWP) look for in applications and this guide contains a helpful list of definitions.

A quick guide to...

The WHO Functional Class

The World Health Organisation (WHO) functional class system was created to define the severity of an individual's symptoms and how they impact on day-to-day activities, so understanding these definitions may be helpful when completing your welfare applications.

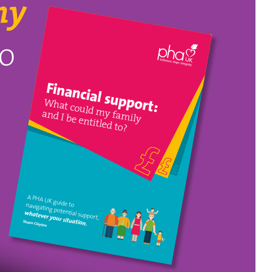
A quick guide to...

The 3-stage appeals process

Around 80% of people who appeal eventually get what they are entitled to. This guide helps you find out more about the stages involved.

> *"We know that navigating the complicated benefits system can be difficult and frustrating, so we've put together these simple reference sheets to help. We've aimed to address the areas you tell us you struggle with the most - but if there's anything else you think would be useful, as always, please let us know."*
>
> **Shaun Clayton,**
> **Membership Services Director, PHA UK**

Want to know more about applying for benefits? Our special publication, ***Financial support: What could my family and I be entitled to?*** is also available to order for FREE from **www.phauk.org**



Download these FREE guides instantly today at

Stronger together

A social network is providing a powerful connection point between family and friends during a health journey. *Charlotte Goldthorpe* takes a closer look.

CaringBridge became a non-profit organisation in 2002 and allows people to send updates about their health journey to friends and family and receive support and encouragement through difficult times.

The main mission of CaringBridge is to amplify the love, hope and compassion in the world, making each health journey easier. Since 1997, more than half a million CaringBridge websites have been created and its reach extends to 236 countries and territories.

The idea for CaringBridge came from founder Sona Mehring who was asked by a friend to let people know what was happening when she went into premature labour. Instead of making dozens of emotional and time-consuming phone calls, she decided to create a website. That same night, her friend's baby was born.

So how does it work? Firstly, you'll need to visit the CaringBridge website to create your own profile page to keep loved ones up to date. Then, simply post an update to your journal and immediately spread the word about your situation. People can follow you and receive texts and email updates when you share a post. Your friends and family will interact with your posts by clicking on the heart or writing comments. They can also send thoughts and well wishes.

As well as updating family and friends, CaringBridge is also a way of engaging with your community - you can post a personal fundraiser, coordinate tasks, include links to other websites and write down what you need help with.

CaringBridge is safe, secure and advert free. You can make your page completely private, or if you'd like it to be more of a health journal you can set it to be live for everyone to see.

Every six minutes a new CaringBridge website is started, and hundreds of thousands of comments and well wishes are shared every day. To start your free website to share your PH journey visit: **www.caringbridge.org**

HOW TO CREATE A CARINGBRIDGE SITE

1. Get started
Create a website for yourself or a loved one in under five minutes! Think of it like setting up a new Facebook profile.

2. Personalise it
Give your CaringBridge website a name, add a main site photo and select a cover photo.

3. Post an update
Tell people what's happening with a quick update or longer journal entry. Your site is all about your PH and what you need to say and hear.

4. Get support
Write a message explaining ways family and friends can best help you. You can even link your CaringBridge website to a personal fundraiser or other helpful tools.

5. Share it
Invite people to visit or share a link on other social media sites.

The PHA UK's view

"Having a rare disease like PH can make explaining your situation to friends and family difficult to deal with. Questions and concerns build up and it's hard to know how to communicate how you are feeling. Connecting with people through your own personal CaringBridge website gives you one centralised, private place to share health updates and request help when you need it."

Monitoring your *mental health*

Living with a long-term health condition such as pulmonary hypertension can leave you more susceptible to mental illnesses like depression and anxiety. Here, Psychological Wellbeing Practitioner *Philippa Horn*, who has PH herself, calls on patients to seek help when they need it.

“Our physical and emotional health are equal and intertwined components of wellbeing.

Research shows that people with long term health conditions are twice as likely to have depression. It also shows that when people have depression they are less likely to look after themselves properly, and less likely to comply with their specialist care plan - which in turn will lead to increased personal distress, and deterioration in physical health.

When people have depression, they may isolate themselves from other people because they might feel they cannot be bothered, it is too much effort, or there is nothing apart from illness to talk about.

When we avoid people, we are missing out on an opportunity to have fun, and there may be a tendency to fill the time instead by worrying about our health conditions, and focusing on negative thoughts. If we constantly avoid our friends we can lose friendships, which is something I frequently hear in my work.

Anxiety may also be an issue, and for those with more than one long-term health condition, this can be exacerbated.

It is therefore vital that all PH patients keep an eye on their mental health and get help when they need it.

*An individual's view of both physical and mental illness will be influenced by their family culture, how they were brought up and memories of loved ones. But depression, anxiety and panic disorder are very treatable conditions, **so please do not allow any possible perceived stigma of mental health to prevent you from accessing services**. Treatment is delivered in a variety of formats nowadays - face to face, in groups, over the telephone or using technology, for example a computer package.*

Accessing support

If you have concerns about your mental health, the first step is to visit your GP. Quite often, they will suggest you contact your local Improving Access to Psychological Therapies (IAPT) service for an assessment. Improving Access to Psychological Therapies is an NHS (England) initiative to provide more psychotherapy to the general population.

Any person can contact their local mental health team via telephone or online, so if you would prefer to self-refer, instead of going via your GP, this is an option.

Depending on where you live, they might be called a Wellbeing Team, Mental Health Matters, Healthy Minds, or a different name entirely.

Once you have contacted them, after giving some demographic details, you will be booked in for an assessment. These are mostly done over the telephone, although face-to-face assessments are available if you have a hearing impairment.

During the call, you will be asked to complete standard questionnaires which measure symptoms of low mood and anxiety (known as PHQ-9 and GAD-7). Some of the questions will be around risk to yourself, so don't be alarmed by this. Everything you say in the assessment is confidential (unless there are concerns about risks to yourself or others) and the call usually takes about 45 minutes.

*You will be asked to describe what your main problem is and what it is that you would like some help with. **Some people do get upset when having their assessment - you are only human so please do not be embarrassed; the person carrying out the assessment will be caring and experienced.***

At the end of the assessment, you will jointly decide what is the best treatment available. It might be counselling, cognitive behaviour therapy (CBT) or guided self-help – which is psycho education about low mood, unhelpful thinking habits we can have, relaxation, increasing your activities, worry management, anxiety and sleep.

Some geographical areas run groups specifically for people who have long term health conditions, which include topics such as pain management, and pacing.

Most areas run groups for anxiety and depression, which are education based. Do not feel that it is 'group therapy' - it is all about learning techniques for coping and learning what maintains cycles of depression or anxiety.

***On a day-to-day basis we can do things ourselves to enhance our feelings of wellbeing.** This includes eating well, as this affects our physical health and emotional health, exercising, getting out of the house, seeing friends and connecting with other people. Setting goals, however small, can help. And remember - confidence does not develop through thinking alone; we need to do things to develop it.”*

My story

*“**At the time of being diagnosed with PH in 2009, I worked part-time in administration for the NHS and was part way through a counselling diploma.** I returned to work on a phased return seven months later, and off I would go to work with my packed lunch and oxygen cylinder. I managed to complete my counselling diploma the following year.*

In October 2015, I got a job as a trainee Psychological Wellbeing Practitioner, a golden opportunity. I was required to work full time and attend university two days a week and complete academic study. This was a huge challenge for me, working full time after working part time for 27 years. I knew that I was stretching myself physically and academically, but if I wanted a more rewarding job, I needed to take the risk and try.

Fortunately, I passed the course in October 2016 and secured a full-time post as a Psychological Wellbeing Practitioner. This is a job I love. I spend my time doing assessments for people to consider if they are suitable for services and delivering low intensity cognitive behavioural therapy treatments. I have also recently completed additional training in long term health conditions.

***I do enjoy the challenge of learning and want to help people who have PH assess their mental health.**”*

According to the NHS, symptoms of DEPRESSION can include continuous low mood or sadness, feeling hopeless and helpless, low self-esteem, feeling tearful, guilt-ridden, irritable, and having difficulty making decisions. Physical symptoms may include a change in appetite, disturbed sleep, loss of libido and lack of energy. Symptoms of ANXIETY can include restlessness, a sense of dread, feeling constantly 'on edge', difficulty concentrating, irritability, feeling sick and insomnia.

Visit **www.nhs.uk** for the full list of symptoms.

PHA UK TRUSTED Partner

AnxietyUK

Members of the PHA UK have access to a free, dedicated helpline and email service run by Anxiety UK. If you or your family have concerns about your emotional wellbeing, call **0844 332 9010** or email **phauk@anxietyuk.org.uk**. See p46 for further details.

No cure, *always hope*

2018 marks a decade since *Tess Jewson* was diagnosed with PH and she's more determined than ever to keep on living life to the full. In this special feature to mark her anniversary, she looks back on her journey.

"It was January 2008 and after a fantastic family Christmas it was time for me to return to college. I was very excited to see my friends and get back to studying for my A-Levels, as I wanted to go to university to study music. We decided to go bowling one lunch break and on the walk back to class, I suddenly felt really ill. My chest was pounding, I had severe breathlessness and I fainted. I was rushed to my local hospital and then transferred to one in London.

I had already been a respiratory patient there for ten years and at every consultation I complained of suffering with severe breathlessness, but each time I was told my asthma was getting worse and a new inhaler was prescribed.

On this particular day, I was put into the intensive care unit and once stabilised, was moved to the respiratory ward. I had a right heart catheter, ECG, MRI scans, multiple blood tests and x-rays. We were told the hole in the heart I was born with hadn't closed up and it had led to pulmonary hypertension with Eisenmenger's syndrome. It was incurable. We were shocked, and not ready for this devastating news, as we had previously been told my hole had closed up. I was given a short prognosis and told they couldn't close up the hole, as it would kill me instantly.

The thought I might die, before I was even 18, was too much to bear. I felt like my world had come crashing down. I cried and cried and felt my dreams were all shattered.

My consultant then said my only cure was a double lung and heart transplant, but that I had many tablets to try before I needed to start worrying about that. I immediately started Sildenafil and soon noticed an improvement. My parents stayed in hotels near to the hospital throughout and family and friends visited over the months. I remember speaking to a lovely lady who was in the bed opposite me, and to cheer ourselves up we would score each male doctor or nurse out of ten!

Coming to terms with my diagnosis

None of my family and friends had heard of pulmonary hypertension, so we were given leaflets to explain it. We went on Google, which sent fear into us, but I became a member of the PHA UK who introduced me to the online support group where other people had PH too. It was a relief to speak to others with the same condition, knowing they understood what I was talking about. I had spoken to many for a few years, so when I attended my first PHA UK patient conference, it was wonderful meeting them in person. One friend I speak to a lot is Tina Pickering. We call ourselves 'twinnies' as we both have exactly the same PH, and also the same positive and determined outlook on life. As Tina says; 'it lives with us, not the other way around!'

After my diagnosis, at my request my teachers compiled my coursework, so I could continue studies whilst in hospital and still take my exams when I was discharged in the May. I had to get used to the changes in my life - walking slower than everyone else, taking lifts instead of the stairs, and taking tablets three times a day. It was very frustrating making these changes, but I was still alive! I had my family, friends and my music and that's what got me through. My continued studies paid off. I passed all my exams and my place at the University of Southampton was confirmed.

Moving on

Attending university was scary, especially being recently diagnosed and three hours away from home. My mum couldn't just pop down the road if I was poorly. However, being the positive and determined person I am, I grabbed university life by both hands and enjoyed every minute. I had to pace myself and sometimes I'd push the limits and go out partying until the early hours with my friends, but I always made sure I could rest all of the next day. Yes, I had my ups and downs, and my Sildenafil dosage was increased due to the stress of my studies, but for the majority of the course, I managed my PH well. I graduated with a music degree in 2012.

Afterwards, I moved back home to live with my parents and opened up my own music teaching business. It worked well as I could choose my own working hours and fit it around hospital appointments.

In December 2014, my Dad sadly passed away, which knocked us all. He was the rock of the family and kept us together throughout my diagnosis. He always remained positive that I would continue to do whatever I wanted despite PH.

In hospital in March 2015

Around the same time I met Terry, who is now my husband. I told Terry straight away about my PH, as even though it was invisible for me, he had to know the truth. Many have run for the hills, but he stayed!

Also in that year I stopped teaching and had a career change. I wanted to help others with disabilities whilst still using my musical talents, so I studied to become a music therapist. I graduated... ☞

Tess keeps a blog and Facebook page dedicated to her PH journey. Visit www.musichelpsmebreathe.blogspot.com and www.facebook.com/tessandph

You can also follow her on Twitter @maritess_mt, where she uses the hashtag #NoCureAlwaysHope to share her PH experiences.


With my parents on graduation day in 2012


With Terry and Izzy


Celebrating my 27th birthday with friends

with a Masters degree in Music Therapy and I currently work with children with severe learning disabilities, which I absolutely love.

My relationship with Terry went from strength to strength and we got engaged in February 2016. We bought a house later that year and married on April 27th, 2017. We were fully insured in case of any complications caused by my PH, but it was all ok and we had a wonderful day. I was so excited that I could walk down the aisle without any disability aid and I was symptom-free for the whole day. We recently became a family when we bought our puppy, Izzy.

Looking back

Looking back on the last ten years, I can't believe how far I have come. I have not let PH stop me and I have achieved the goals I set before my diagnosis.

It hasn't been easy. There are always struggles, thoughts of 'why me?', fears and tears. But there is also happiness. Throughout my journey I've had amazing support from family, friends and my specialist PH team. Some friendships have been lost, but not everyone will understand.

I love being involved in anything that raises awareness of PH and I will continue to tell my story to whoever listens. I don't know what my future holds, but with the love and support of my friends and family, especially my husband and mum, I will always keep positive and hope for a cure. One thing is for sure - I will continue to live life to the full! ”

> “*Looking back on the last ten years, I can't believe how far I have come. I have not let PH stop me and I have achieved the goals I set before my diagnosis.*”


With my fellow PHA UK member and 'twinnie' Tina

How we spend **your mon£y**

As a charity, we don't get any financial support from the government. We rely heavily on the kind fundraising and support of others to help us carry out our work and here, we'd like to share with you how your donations are used. This is how we spent your money between October 2016 and October 2017.

4%

££££

General running costs

A small amount of our income – 4p out of every £1 – goes on general running costs to keep the charity operational. Our office in Sheffield doubles up as a resource centre, which enables us to deliver educational workshops to medical professionals. In the year October 2016-17 they covered topics including managing breathless patients and signposting to benefits. Our resource centre also hosts meetings between specialist centres and is the nucleus of our **PHocus2021** activity, providing a northern base for collaborative working with strategic commissioning bodies.

21%

£
££££££££££
££££££££££

Research and survey work

As well as conducting our own research, we provide grants to individuals and partner with organisations. Between October 2016-17 our research work focused around the **Living with PH survey** (the largest of its kind in the world), a subsequent study into the financial impact of PH, and a major cohort study into the lived experience of pulmonary hypertension – conducted in association with the University of Manchester. We also funded research around the need for palliative and supportive care in PH, which will help inform our work in this area in both the near and long-term future.

34%

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Membership support

Our small head office team provide support via telephone and email, and we run dedicated social media channels (including an online support group). In May 2017 our patient conference brought patients, loved ones and professionals together in Oxford and we produce four issues of this magazine, Emphasis, each year. Between October 2016-17 we also produced support publications including a new guide to obtaining benefits, a pocket guide to PH, and re-prints of our flagship publication, '**Understanding pulmonary hypertension**'. Our partnerships with Anxiety UK and Turn2Us provided dedicated support for emotional and financial issues linked to PH.

41%

£
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Raising awareness of PH

Between October 2016-17 our work in this area included running the charity website; public relations activity around the results of the Living with PH survey – including the production of two films; launching **PH Awareness Week**; and attending exhibitions to raise awareness in the acute and general medicine sector. We launched **PHocus2021** to raise awareness in political circles and push for policy changes, engaging with decision makers at the highest level and launching a dedicated website and awareness programme. We also raised awareness amongst professionals via our medical education programme, training and workshops, and supported fundraising events with branding and merchandise.

For full details of our fully audited accounts, visit the charities commission website: www.gov.uk/government/organisations/charity-commission
*Source: Charity Choice (www.charitychoice.co.uk)

A back-to-basics movement created by a young doctor who died of cancer is putting compassion at the heart of healthcare. *Deborah Wain* reports.

Hospital doctor Kate Granger found herself as a patient when she was diagnosed with a rare and aggressive form of cancer, aged just 29. And what she discovered in her subsequent interactions with some medical professionals dismayed her.

The failure of staff to even introduce themselves – including the doctor who broke the news her illness was incurable – left her feeling more of a condition than a human being. When someone did introduce themselves, it made all the difference.

Kate's response to her unique insight was to begin a back-to-basics campaign to improve the patient experience in hospitals by asking healthcare staff to make a pledge to introduce themselves to their patients.

What began as a hashtag on the social media platform Twitter, #hellomynameis has grown into a worldwide movement, continuing beyond Kate's sad death in 2016, five years after her diagnosis.

Here in the UK, the #hellomynameis campaign has seen hundreds of thousands of healthcare staff sign up - nurses, doctors, therapists, receptionists, porters, domestics; in fact, staff in all roles.

Kate's strongly-held belief was that an initial introduction went far deeper than being an act of common courtesy.

She wrote when creating the campaign: ***"Introductions are about making a human connection between one human being who is suffering and vulnerable, and another human being who wishes to help. They begin therapeutic relationships and can instantly build trust in difficult circumstances.***

> *"In my mind #hellomynameis is the first rung on the ladder to providing truly person-centred, compassionate care."*

Kate, from West Yorkshire, was working as a junior doctor when, in 2011, her life and that of her husband Chris Pointon were turned upside down by her cancer diagnosis. In 2012 she stopped receiving chemotherapy and returned to work, qualifying as a consultant geriatrician.

It was during a hospital stay in August 2013 with post-operative sepsis, that Kate noticed that often staff looking after her did not introduce themselves when delivering her care and this felt very wrong.

Kate's vision was to use social media to urge healthcare staff to remember the importance of introductions. She tapped into the online following she had developed with a blog about her illness and the hashtag took flight.

Since its launch in 2013, **#hellomynameis** has generated over 1.8 billion online impressions with an average of six tweets an hour.

Support for the campaign has come from celebrities like Richard Branson and Kylie Minogue, as well as politicians including the Prime Minister, Theresa May.

The Mid Yorkshire Hospitals Trust, where Kate worked, was among the first trusts to sign up to the initiative and eventually NHS trusts up and down the country followed suit. Kate and husband Chris visited a number of them raising awareness of the campaign slogan.

Kate's contribution to changing practice was recognised in 2014 when NHS England and NHS Employers launched the 'Kate Granger Awards for Compassionate Care', honouring both individuals and teams. Kate was subsequently given an MBE for her services to the NHS and improving care, along with other awards.

Kate, who also wrote two books charting her battle with cancer, was taken aback by the extent to which her experience had inspired others in the NHS and beyond. She described the response as "overwhelming".

"What has struck me since I began to publicly share my experiences as a patient is just how powerful the voice of a clinician living life on the other side can be. I never dreamed anyone would listen to what I had to say but now my voice has been heard I am determined to use it in the most positive way possible in my remaining time," she said.

Kate's death at St Gemma's Hospice, in Leeds, aged 34, brought forth an outpouring of tributes from people who knew her personally and others who didn't but had been touched by her spirit and message.

Health Secretary Jeremy Hunt tweeted about Kate: *"Her legacy promoting a more human touch and compassionate care will outlive us all."*

Then NHS medical director Sir Bruce Keogh said: *"Kate Granger was an inspiration to us all and her #hellomynameis campaign and the Compassionate Care Awards named after her will be her legacy to the NHS and a lasting tribute to her memory."*

Kate's widower Chris is currently on a tour to spread the **#hellomynameis** message at various hospitals, trusts, conferences and universities across the globe. NHS trusts are now sharing ideas about how to boost person-focussed care. ●

The PHA UK's view

Iain Armstrong, Clinical Nurse Specialist and Chair of the PHA UK, said:

"Through the #hellomynameis campaign, Kate has left an important legacy and her work has emphasised the vital need for patients to be treated with compassionate care that centres around them, not their illness. Introducing yourself to someone by name is basic manners, but it's shocking how often this doesn't happen. Whether it's PH, cancer, broken bones or any other chronic or acute illness, patients are people not numbers. An introduction – a little bit of humanity – goes a long way. Our NHS does an incredible job of looking after people during times of severe austerity, and whilst as clinicians we may not be able to control budget cuts, we can make small changes that will make big differences to those we see and treat. Kate herself said that the #hellomynameis campaign is the first rung on the ladder to providing truly person-centred compassionate care - and it's up to us as medical professionals to get to the top."

The exercise programmes inspiring people to MOVE MORE

Exercise programmes underway in Sheffield and Glasgow will help to determine the health benefits of exercise therapy for people with pulmonary hypertension in the UK. *Charlotte Goldthorpe* reports on the findings so far.

PIONEERING PROGRAMME IN GLASGOW

An exercise programme currently taking place at The Golden Jubilee National Hospital, Glasgow, aims to reduce symptoms, improve quality of life and heart function. The study was inspired by a pioneering programme in Germany.

Led by Dr Martin Johnson, along with the research team which includes a dedicated physiotherapist, medical and nursing staff at the Scottish Pulmonary Vascular Unit (SPVU), the study involves an initial three-week residential phase at the Golden Jubilee Conference Hotel with individually-tailored and supervised daily exercise training, either one-to-one or in small groups. Following this, there is a 12-week home exercise programme supervised over the phone and by email.

A total of 40 patients will participate in the study up to the summer, with 26 having already completed the programme. The results so far are positive, in areas including changes in pulmonary artery pressure, the six-minute walk test, muscle strength and exercise tolerance.

The study is due to be completed in early Autumn and it's hoped the results will be analysed and published in scientific journals, as well as being presented at scientific meetings.

The team has already presented some of the initial results at the Pulmonary Hypertension Forum in Vienna, and the European Respiratory Society Congress meeting in Milan, last year.

The results

Research physiotherapist, Joanna Ford, said: *"We are really pleased with the results of the study so far. Many of our patients have been unwell for some time, but to see them gain confidence through the programme is very rewarding.*

"Initial results have shown significant improvements in exercise capacity, quality of life and breathing function and going forward we hope to gain more insight into how the therapy is benefiting patients. Our ultimate goal is to establish a dedicated rehabilitation service so many more patients can benefit from exercise therapy."

Elaine's story

Elaine Fiddes decided to take part in the programme at the SPVU after losing both her mum and son to PH.

She said: *"When I was invited to take part in the exercise study, my immediate thought was, how could I not?* ***I wanted to contribute in any way possible to defeat and eventually eradicate this horrible condition.***

The study has given me more confidence in knowing what I can achieve and what a safe exercise tolerance is for me. I feel that this condition is a bit like a pendulum swinging downwards. Taking exercise has pushed the pendulum back, and although it will inevitably swing downwards again, the exercise appears to be considerably slowing down the swing of the pendulum.

To me, the study has been life-enhancing and life-extending. The statistical data from my walk tests and from my right heart catheterisation appear to show this too.

The best part of my involvement with the SPVU has been the new friendships I have made with a number of people. *The professionals are fantastic, kind, supportive and friendly people who are a credit to their profession. Everyone I met showed great commitment to the study and were intent on making the experience for the patient as pleasant as possible. I have also made new friendships amongst the patients on the study, and keep in regular contact with some of them by phone and text.*

After having such a positive experience on this exercise study, I have now embarked on another. I would urge anyone who is given the opportunity to take part if it is feasible for them."

MOVE MORE EVERY DAY

A pilot exercise intervention at the Royal Hallamshire Hospital in Sheffield is encouraging PH patients to be more active. *'Move More Every Day'* is being tested for some PH patients who have been receiving treatment for at least three months at the Sheffield Pulmonary Vascular Disease Unit (SPVDU).

As well as educating patients and offering advice on exercise techniques with a trained clinical specialist physiotherapist, many are referred for pulmonary rehabilitation (PR) in a community service in the patient's home region. This consists of a physical exercise programme intended for people who are severely breathless, which is run by a team of physiotherapists, nurses and occupational therapists.

A course of PR usually lasts six to eight weeks, with two sessions of around two hours each week. PR courses are held in local hospitals, community halls, leisure centres and health centres.

Carol Keen, clinical specialist physiotherapist at the hospital, said: *"Our project looks at how we can get patients fitter and stronger to help get the most from their treatment. We know PH is a progressive disease, so we need patients to invest in their future: exercise is one thing that might help them to control their condition. All of this means they may be independent for longer and enjoy a better quality of life."*

The results

In the first four months of the project, over 100 patients were invited to take part. Half of those were referred for pulmonary rehabilitation in their community who wouldn't have otherwise received the therapy. Around 15 per cent were already taking part in regular exercise and were encouraged to keep going.

Around 20 per cent fell into the 'other' category, which could include being too unwell or not able to attend pulmonary rehabilitation classes. In some cases, these patients were referred to other therapy services. A handful of patients were offered rehabilitation or exercise advice, but felt it was not right for them.

When people finish their rehabilitation, the checks that are usually carried out when they come to clinic - like their walk test and their emphasis 10 questionnaire - will be looked at to see if the exercise has made a difference.

Carol said: *"Completing a course of pulmonary rehabilitation is a good way to learn how to exercise safely and at the right level for you. Most people enjoy the course as it builds confidence and it's great fun meeting others in a similar situation."*

Brian's story

Brian Salt was diagnosed with PH in October 2016.

He said: *"After a heart operation I lost all confidence and I couldn't walk very far at all. I enjoyed gardening, but even this was too much and simply walking around the corner to the bus stop was becoming difficult.*

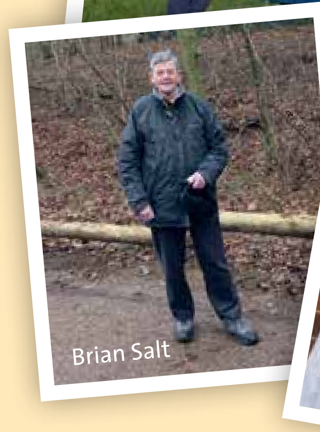
I was offered pulmonary physiotherapy which involved taking part in supervised tests on the treadmill and bike to assess my fitness levels. I attended pulmonary rehabilitation classes twice a week for eight weeks. Not only did it build up the strength in my legs, but it massively built up my confidence.

The goal after the eight-week programme was to walk two miles, which I did. I was extremely proud and it spurred me on to continue on my exercise journey. I now attend one session a week at the community hospital near where I live, which is just a short bus ride away.

Since starting exercise therapy, I now enjoy a better quality of life and generally feel healthier and happier. *It's given me the boost I needed and I can now go out walking without the need to stop to catch my breath as often as I had to before the therapy.*

I would definitely urge others with PH to take part in this type of programme if they have the opportunity. *At first, I wasn't sure what to expect and wondered if I'd be able to do it, but the sessions are closely monitored and there's plenty of help and support available. The staff encourage you to go at your own pace so there's no need to worry about pushing yourself to the limit."*

Elaine Fiddes



Brian Salt

Carol Keen

Always speak to your specialist centre before embarking on a new exercise routine.

Fundraising roundup

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

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

£2,331 RAISED

Prosecco & pizza for PH

Kelly Holliday from Workington held a prosecco and pizza night for 70 family and friends to raise money in memory of her friend, Claire Dempster, who died in 2016. Kelly said: "We all loved Claire so much and we wanted to do something to mark her 40th birthday and raise awareness of pulmonary hypertension." The prosecco and pizza was kindly donated by local businesses and money was raised from bingo and a raffle.

Cycling Santas

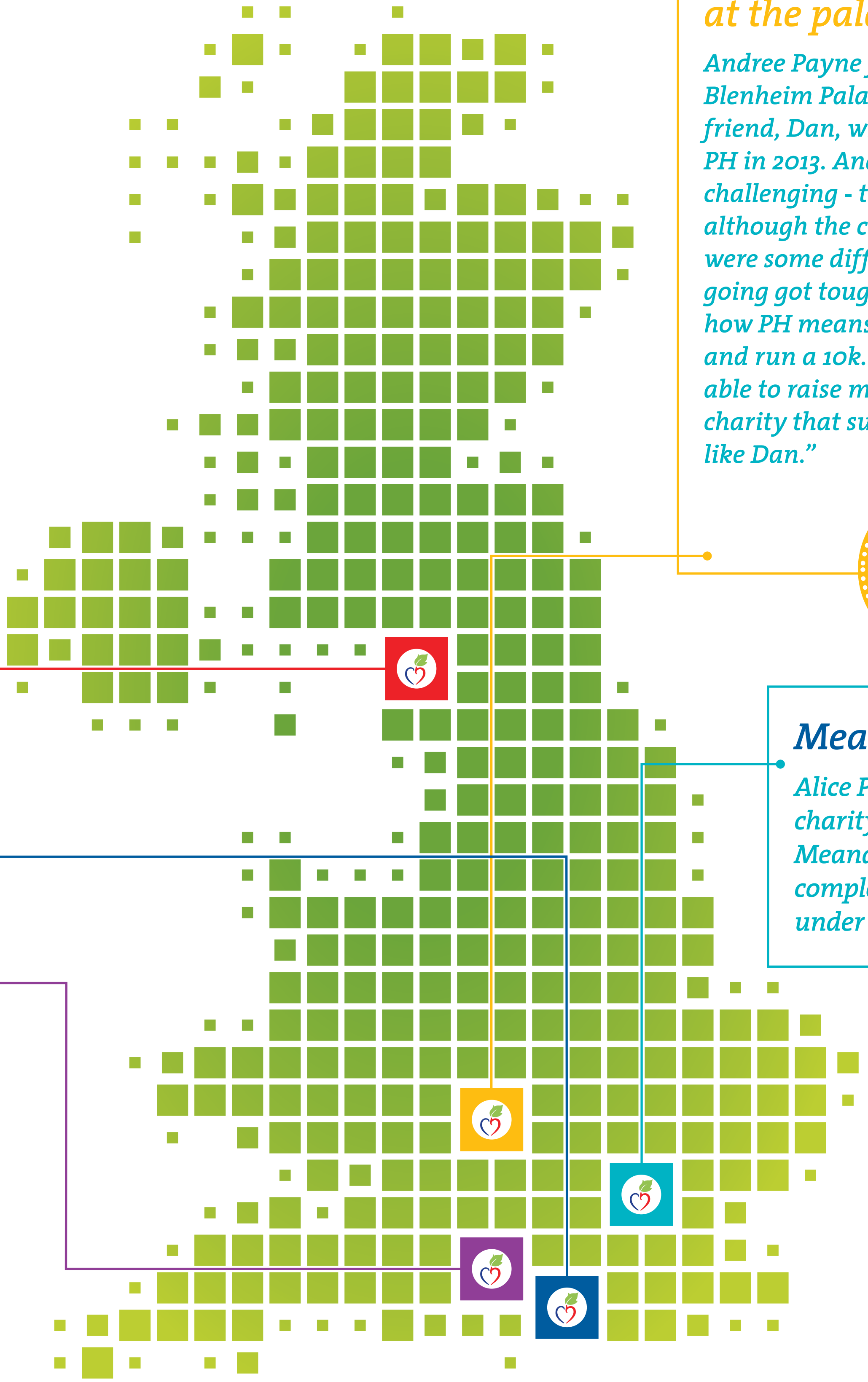
Friends of Dave and Lea Acres spent a sunny winter's morning walking, running and cycling around Chidham in West Sussex dressed in Santa outfits. They were then treated to tea, coffee, mulled wine and a great assortment of cakes and mince pies, all of which had been kindly donated. Dave and Lea raised money for the PHA UK as their son Will was diagnosed with PH in 2016.

£524 RAISED

Winchester workout

Paul Stout from Winchester put his running shoes on to raise money for PHA UK by completing the Winchester half-marathon. He ran it in support of his sister Mary, who was diagnosed with PH a few years ago. Paul said: "I've never run that far before but it was really motivating to train and complete the half-marathon knowing what I was raising funds for."

£753 RAISED



Pavement pounding at the palace

Andree Payne from Oxfordshire ran the Blenheim Palace 10k in support of her friend, Dan, who was diagnosed with PH in 2013. Andree said: "It was definitely challenging - the course is pretty hilly and although the crowd was amazing, there were some difficult moments. But when the going got tough I thought about Dan, and how PH means he can't choose to get up and run a 10k. I am so thrilled that I was able to raise money for a fantastic charity that supports people like Dan."

£223 RAISED

Meandering the Thames

Alice Parker chose PHA UK as her charity when she ran the Thames Meander half-marathon. She completed the 13-mile run in just under two hours. Alice said: "I decided to run the half marathon because my little brother suffers from PH. He has always been so brave and determined not to be treated any differently from anyone else and has always remained so positive. It felt great to raise money and do my bit and I will definitely be trying to raise some more this year!"

£879 RAISED

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

People with PH just want to be heard...

PHA UK member *Sharon Grainger* wrote to Emphasis to share her experiences of chronic thrombolic pulmonary hypertension (CTEPH). In this special letter, she reveals her frustrating journey to diagnosis and how surgery saved her life.

Sharon Grainger
Oldbury, West Midlands

Dear Editor,

I'm writing this because it's really important to me to share my story with other people. This is mainly because until I was diagnosed with this disease, I didn't really know what it was - and therefore I feel it's important for me to get the message out there to others so that they don't find themselves feeling alone and frustrated.

I was diagnosed with chronic thrombolic pulmonary hypertension (CTEPH) in November 2016 after my symptoms got progressively worse.

Originally, my disease began in 2012 when I suffered a pulmonary embolism. At the time, no one knew what was wrong with me. I was suffering from shortness of breath which would not go away and so on Christmas Day 2011, I decided I had to go to the walk-in clinic as I couldn't take much more of the breathlessness.

When I arrived at the walk-in clinic to see a doctor, **I was immediately dismissed as a time waster and told that I was 'just having a panic attack'**. The doctor who saw me told me to get a paper bag and breathe into it and then I'd be fine. I went away and wasn't convinced by what I was being told so I decided that I would go to my own doctors, as soon as they were open, after Christmas.

So, after several visits back and forth to my doctor, I was sent to hospital to have a D-dimer test and chest X-ray. It was finally the D-dimer test that picked up something wasn't right. I had a phone call from my doctors, who asked me to come straight to the surgery and from there I was sent back to the hospital. After lots of questions and a VQ scan, I finally got the diagnosis of a pulmonary embolism. From then I was put on heparin and warfarin which I stayed on until June 2016.

Fast forward a couple of years later and I was back at the doctors complaining of shortness of breath from exercise and constantly coughing during the night which was making me wake up. My doctors diagnosed asthma and so I was given a reliever inhaler to start with. This didn't seem to do much and so then I was given preventer inhalers.

At first, this seemed to do something and I thought it had helped, but it wasn't until the beginning of 2016 that I started to think something wasn't right. I was constantly at the doctors. First with a chest infection and next with what I thought was phlebitis in my legs. Then I began to notice a problem; my toes were painful and blue and I couldn't understand what was causing it. A friend of mine at the time had also noticed my lips were blue.

I started to feel like I was spending my life at the doctors. My doctor referred me back to a haematologist and then a rheumatologist. Unfortunately, the haematologist decided to take me off my warfarin medication to do tests to see if they could find out what the problem was. This led to me having another PE and I went back to hospital.

PTO

Me today

After my operation

Doctors at the hospital were confused about why I had been told I had asthma as they didn't believe asthma was causing my symptoms. However, **I still wasn't getting answers to why I was feeling so ill and I began to feel more and more frustrated.** I felt like I was going around in circles and not getting very far.

I spent the next few months gradually getting worse. I was constantly tired, breathless doing simple activities and felt so frustrated that no one could answer why I was feeling like this. It wasn't until I went to see the rheumatologist that someone started listening to my symptoms. As soon as I described my symptoms, the rheumatologist decided it was time to send me for specific tests. These included a lung function test, echocardiogram and some chest X-rays. **It was the echocardiogram that finally picked up my pulmonary hypertension.**

I was then referred to a respiratory consultant who had knowledge about the illness. Unfortunately for me, the day before going to see the consultant, I fainted and passed out at home from walking up the stairs. I immediately panicked when I came round as I knew this was really not right. Fortunately for me, someone was at home and sent for an ambulance. I got to hospital and explained I knew what had caused the problem. I got quite angry whilst in A and E as the doctor was going to send me home but then they came back and said there were abnormalities with my heartbeat. Thank goodness, I was kept in, as the following day I was taken to see my consultant who decided that I needed to be sent straight to Papworth Hospital.

For the first time in years, I felt like I was listened to. Immediately, within ten minutes of arriving at the hospital, members of the PH team came straight to talk to me to find out what was going on. **It was such a relief.**

My pulmonary endarterectomy operation happened quite quickly because my illness had become so severe. They did all the necessary tests but by the time they had been completed, I was fainting and collapsing on the hospital staff. So, within two weeks I had my surgery.

Since the pulmonary endarterectomy operation, I've not looked back. It wasn't a 100 per cent cure but it did help to clear the main problem. I'm still classed as having PH but my condition is treated with tablets. I thank God that I got to the right place, just in time. **I'm grateful and thankful to all the staff at Papworth Hospital** and especially the surgeon who removed the clot tissue from my lungs. I'm lucky my type of PH had a potential cure as I know people with other types do not have this option unless they have a transplant.

People with PH just want to be heard. So many people get misdiagnosed because of a lack of knowledge about this disease. It's time something is done about it.

Thank you for listening to my story. I hope this message will be heard.

Yours faithfully

Sharon Grainger,

Oldbury, West Midlands

Lacing up for London

Four fundraisers will be pounding the pavements of the capital in April, as they take on the world-famous London Marathon for the PHA UK. Here *Michael*, *Ellie*, and brothers *Paul & Mark* share their reasons for running.

London Marathon 2018
Virgin money

Ellie Rose Price

> *I am running in memory of the beautiful Alexandria Beeson, who tragically lost her fight with pulmonary hypertension in 2012. My husband ran the London Marathon in 2013 for the PHA UK in Alex's memory, and her mum is coming over from Los Angeles to support me on the day. In her words, Alex was 'an extraordinary young lady loved by everyone'. I have never run a marathon before; I was a complete beginner to running before embarking on this challenge. I am feeling nervous, worried, and proud of pushing myself to new limits. It was probably not the right time to start such a huge challenge having just returned to work after having my baby a year ago, but I feel so determined to complete it for a charity close to my heart.*

www.justgiving.com/fundraising/ellie-price18

Michael Leafe

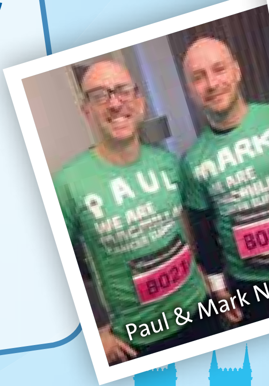
> *My sister Jenny suffers with PH and by running the marathon for the PHA UK I want to do my bit to ensure that the signs and symptoms of PH are better recognised and to make more people aware of the condition. Jenny is an inspiration to the whole family, and I know that she is a huge inspiration to others in similar positions. So, I'm putting myself through all this gruelling training as a tribute to her. I was due to run the marathon for the PHA UK last year, but a fractured toe derailed my training and I had to pull out. This time, I'm taking it easy and hoping not to aggravate any of those niggling problems! I'll be running on my own, but I'm sure that Jenny and the rest of the family will be cheering me on from the side-lines.*

www.justgiving.com/fundraising/michael-leafe

Paul & Mark Newing

> *We have chosen to run for the PHA UK because our family member and work colleague, Laura Ling, is a PH sufferer. We both ran in the Brighton Marathon in 2016, and are doing it again this year too. Although we know what to expect, we are both feeling excited and a little anxious about the challenge of completing both Brighton and London in the same week. But rest assured, we will give it our all!*

www.justgiving.com/fundraising/mark-newing



Paul & Mark Newing

Michael Leafe

Ellie Price

Good luck and thank you to everyone taking on sponsored runs, bake sales, sky dives, and more for us over the next few months. If you'd like to see yourself in Emphasis, email editor@phauk.org

Major review of PIP applications – *what you need to know*

At the end of January, the Department for Work and Pensions (DWP) caused ripples when it announced that every person receiving *Personal Independence Payments* (PIP) would have their claim reviewed.

Department for Work & Pensions

It revealed that, following a court ruling that deemed changes to PIP were unfair to people with mental health conditions, 1.6million claims will be looked at again. Around 220,000 people are expected to receive more money.

Why has this happened?

In 2017, changes were made to PIP that meant people who were unable to travel independently on the ground of 'psychological distress' could not claim the enhanced mobility rate.

But in December, the High Court ruled the changes breached the human rights of people with psychiatric problems, and the government announced it would not appeal against the judgement. As a result, **a total of 1.6million of the main disability benefit claims will be reviewed** - at an estimated cost to the government of up to £3.7billion. The process is expected to last up until 2023.

What does this mean?

This, of course, is big news for the PH community. **The Living with PH survey, conducted by the PHA UK in 2016, revealed that 87 per cent of patients believe having pulmonary hypertension impacts on their mental and emotional wellbeing.** And we know that accessing PIP, and appealing if necessary, is difficult and draining for many.

The results of our most recent research into the financial impact of PH will be published imminently, and will serve as concrete evidence of this and many other factors relating to benefits and financial support.

Plus, the results of another major piece of research into the lived experience of PH, conducted by the PHA UK in partnership with the University of Manchester, has recently been accepted for publication in the prestigious BMJ Open Journal – providing further evidence of the mental and emotional impact of PH.

As well as providing important evidence, both these pieces of research will also provide reference points for how PH affects mental wellbeing and finances. **However, it's vital that when completing applications for PIP or any other welfare benefit, you emphasise how your condition affects you personally.**

Our hope is that the results of these research pieces will help make it easier for patients to get what they are entitled to during any review process.

Our advice

Reviewing 1.6million claims will take a long time, and our advice to you right now is not to do anything unless you are approached by the DWP. Demanding a re-assessment may be counter-productive, and we need to know more about how the review will be rolled out. **The PHA UK will be keeping a close eye on developments, and we will update you as soon as we can**. In the meantime, keep an eye on our website, social media and of course, in this magazine. Watch this space! ●

My life with PH

After a bad experience of accessing Personal Independence Payments, *Rebecca Milligan* from Salford was inspired to speak out about PH in the hope of helping more people understand the disease. Here, she opens up about her condition for the first time.

“My symptoms started in 2009 when I was 19. I suddenly started experiencing shortness of breath and chest pain. Once I sat down and I was resting I was fine, but if I got up to walk around I'd feel the chest pain and become very short of breath very quickly.

I went to my local hospital and they took blood samples from my wrist, and sent me for X-rays and C.T scans. Soon they discovered I had a pulmonary embolism (blood clot) on my right lung. They started me on medication which helped to dissolve the clot, but unfortunately it had begun travelling towards my left lung.

I was referred to a specialist PH centre where I underwent further tests and scans and had an IVC filter (an umbrella-like device) inserted into my vein to stop any blood clots caused by deep vein thrombosis travelling from my legs to my lungs. It was then discussed that I should have a heart bypass operation to remove the pulmonary embolism and I was sent for my surgery in September 2009.

I was adamant I didn't want the operation at first. I just couldn't process what was happening, *even when the surgeon told me I would only live for four weeks without a heart bypass. I ended up staying in the hospital for a month.*

The next chapter

From 2009 to 2013 I continued to struggle with the right medication to thin my blood and the shortness of breath and chest pain was still very much an issue. My local GP at the time wasn't very helpful and put my symptoms and issues down to having the heart bypass.

> *It's been really hard financially for me and my partner Tom*

In 2013 I was admitted to my local hospital with suspected pneumonia, and due to a thorough investigation, they also found I had another blood clot - on the same lung, and at the same size as before.

I was transferred to the specialist PH centre again and underwent more investigations, including a right heart catheter. This test led to me being diagnosed with pulmonary hypertension and it was explained to me that the right side of my heart was bigger than my left due to the main artery in my heart being very thick. The gap the oxygen flows through was very small so the heart wasn't getting enough oxygen around my body - which was causing the shortness of breath.

I had never heard of pulmonary hypertension. I assumed it was something connected to the blood clots, so it was a shock to be told it was a separate condition, and that it was extremely rare.

Living with PH

I started a new medication to help open my arteries to allow the oxygen into my body. It works to a certain degree, but because I have a blood clot on my right lung, and now one starting on my left lung, the oxygen levels in my blood are still very low. I have to have oxygen tanks in each room I'm in, and if I go out, I need to take a portable one with me.

> *I have an amazing family and support network and they make me feel as normal as I can be.*

Having PH is very hard. It's draining and confusing. *My mind thinks I'm fine. It thinks I can just shove my shoes on and nip to the shop, or stand and cook tea, or even put a load of washing on - normal, everyday things. But the second I get up to do anything, the symptoms start. I feel suffocated and hot and sweaty, I start gasping for my breath, and the chest pain and the burning jaw ache begins.*

I feel trapped in my own body. I'm only 27, so I should be able to go out with friends for lunch, or go on a holiday or a night out, but I can't physically do it. It's frustrating and I feel alone when I see my friends going out and having a good time.

My life has changed dramatically over the years because of my illness and it's been one thing after another. *I feel like I need a break and to just be normal, just once.*

I've been told I can't have children, because it would put too much strain on my heart. It's upsetting, and hard to talk about. But at the moment, I just need to concentrate on myself.

I have an amazing family and support network and they make me feel as normal as I can be. If I ever need anything they are 100 per cent there. The support I get from all the team at my PH centre is brilliant too and they are absolutely fabulous. They will go above and beyond for you and will take that extra step to help with whatever you need.

Making ends meet

It's been really hard financially for me and my partner Tom as having PH means I can't work. *I used to work as a carer for the elderly, but I was in and out of hospital for long periods and having to get a taxi to work wiped out most of my wages.*

We have to live on Tom's income, which isn't as much as it used to be because he had to change career in order to spend more time supporting me. It put a strain on our relationship.

I have to get taxis to appointments like the doctors because neither of us drive and I find it physically difficult to walk or get the bus.

I wish we could go out like other couples, or have breaks away, but it just costs too much. Organising oxygen to go away is difficult too.

Because PH is such a rare disease, my experiences of accessing benefits have been difficult. *I initially contacted my local job centre about benefits that may be available to me and I was put onto Employment and Support Allowance (ESA), which I still get now.*

I was also advised to apply for Personal Independence Payments (PIP). I was warned that it may be difficult and they were right.

I went to my local Citizens Advice Bureau and they helped me fill out the application form. This was in September 2016, and although it should only take six weeks to hear back from them, they didn't send an assessor out to see me until a year later. I was awarded £58 a week and luckily, they backdated it.

The assessor told me that because PH is not a very common condition, and nobody knows that much about it, they don't think it's that serious and assume it's like high blood pressure.

It made me wonder just how many of us have been turned away from the right benefits because of lack of knowledge, which is why I want to raise more awareness of PH.

This is the first time since I've been diagnosed that I've ever opened up about my condition to anyone.”

PHARMACY FOCUS

Consultant pharmacist *Neil Hamilton* shares the latest news on PH-specific drug therapy.

Generic versions of Tracleer and Adcirca now available

As many of you may know, when new medicines are registered for use in a certain condition, a 'patent' is granted. Rather like a patent for any product, this gives the manufacturer exclusive rights to make and distribute the product. For medicines, this patent lasts 15 years. At the end of that period, other manufacturers have the opportunity to make a 'generic' version. As these generic manufacturers have not incurred any developmental costs, they can sell the product at a much lower cost compared to the brand name version.

Medicines for pulmonary hypertension are no exception to this. For several years, sildenafil has been available generically. In the past few months we have seen two more of our treatments reach the end of their patent. As such, your centre is likely to switch you to generic bosentan from Tracleer and tadalafil from Adcirca.

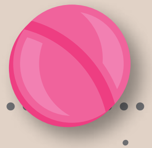
By switching to generic treatments, the NHS will save significant sums of money. I would estimate that savings to the NHS from these switches will be at least £5m per year based on current patient numbers.

From a patient perspective you can be reassured that generics, although cheaper, must undergo the same rigorous quality assurance processes as their branded equivalents. Indeed, some of the recent interruptions to generic sildenafil availability was directly as a result of ensuring quality was being maintained.

If you have any queries about your treatment being switched to a generic, please do not hesitate to contact your specialist centre for advice.

The latest on Selexipag

Selexipag is an oral 'prostanoid' treatment for Pulmonary Arterial Hypertension which works in the body through a similar mechanism to iloprost and epoprostenol. As a tablet, in contrast to a nebuliser or IV pump, Selexipag is straightforward for patients to take. As such it offers potential advantages to some patients who have either not tolerated or benefitted from other treatment options. Despite it already being licensed across Europe and including the UK, it is not currently available to NHS patients.



By switching to generic treatments, the NHS will save significant sums of money.

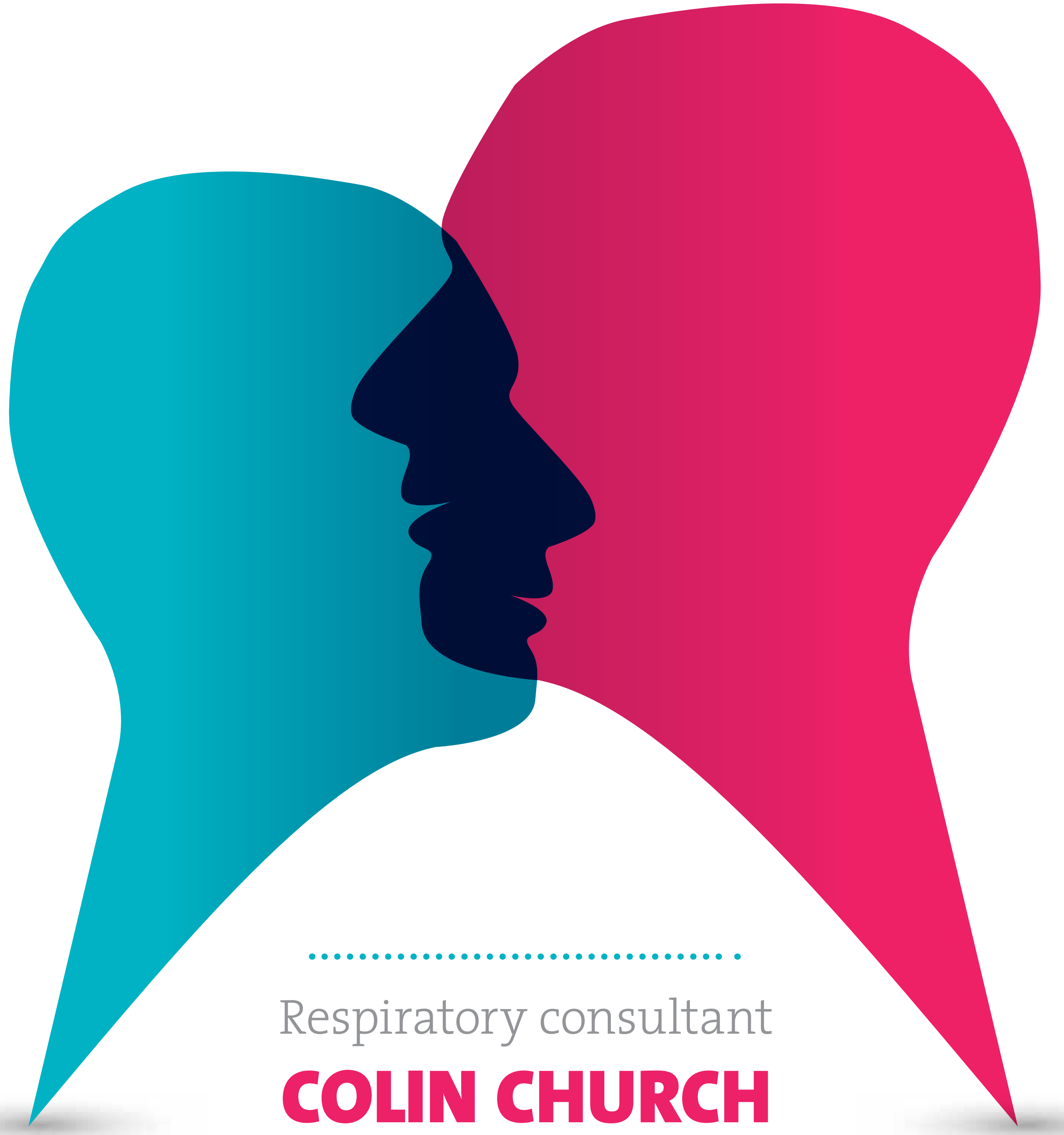
Selexipag has already been turned down once by NHS England and also in Scotland. However, the PH community has taken the opportunity to appeal this decision and request a new review of the clinical evidence. This second evidence review was undertaken by the National Institute of Clinical Excellence (NICE), a body whom most of you will have heard of as they undertake virtually all of the evidence reviews for the NHS. **Generally, a recommendation by NICE that a treatment should be available on the NHS means that therapy must be made available to patients.** However, when NICE undertakes reviews in specialist conditions such as pulmonary hypertension, the conclusion is not so black and white. In this situation, their recommendations will only guide a final decision. That said, a positive review by NICE would be hard for NHS England to go against.

This second review process is almost complete now. NICE have done their evidence review and their recommendations will soon be out for public consultation. Following the consultation, final amendments will be pulled together, and the proposal will go back to a high-level NHS England panel; the Clinical Priorities Advisory Group (CPAG). **CPAG has the unenviable task of deciding which new treatments represent the highest clinical priority,** or in other words which treatments would have the largest benefit to the NHS as a whole. This means that selexipag could potentially be competing against new treatments for cancer, HIV or even new surgical techniques. Once they have 'ranked' the proposals, the cost is taken into account and the budget available for new developments is divided up. It is theoretically possible that all new developments could be afforded and hence all would be approved. However, if this is not the case, once all the budget has been allocated, any treatments below the 'cut off' will not be commissioned. These have up to two more opportunities to go before the panel which meets twice each year.

We all hope that Selexipag will be approved at its second attempt in the May 2018 prioritisation meeting. **You can be reassured that the PH community across all the centres together with the PHA have been working extremely hard with NICE throughout. We will keep you informed of developments at all times but if anyone has specific questions your centre will be very happy to help you.** ●

For more on Selexipag, see page 13

the*interview*



Respiratory consultant

COLIN CHURCH

in conversation with

Charlotte Goldthorpe

Dr. Colin Church is a consultant in pulmonary vascular and respiratory medicine at the Scottish Pulmonary Vascular Unit, based at the Golden Jubilee National Hospital in Glasgow.

He trained in Glasgow, Cambridge, Papworth and Sydney and has completed a PhD in understanding the basic mechanisms of inflammatory signaling in pulmonary vascular remodeling. He has a keen interest in both clinical and basic science research and is a principal investigator on a number of important clinical trials, including looking at novel anti-inflammatory strategies to treat pulmonary hypertension. His basic science research focuses on the interplay of inflammation and hypoxia on the pulmonary vascular cells, in particular the pulmonary artery fibroblast. Colin is one of three consultants in the Scottish Pulmonary Vascular Unit, the national referral centre for patients in Scotland and was appointed there in 2013. He is also one of the principal clinicians involved in the management of venous thromboembolic disease in the Queen Elizabeth University Hospital and sits on the Glasgow Thrombosis committee. .

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

A. *No. Originally, I wanted to be a teacher but then I did work experience at my local hospital and met some wonderful patients. I enjoyed the challenge of trying to diagnose patients and the great team environment that existed. They inspired me to get involved in medicine. I obtained my medical degree at the University of Glasgow and then undertook respiratory training in Australia and Cambridge. At Papworth I worked with Dr Pepke-Zaba and this is when I first became interested in pulmonary hypertension. I did my research in the field of pulmonary hypertension with professor Andrew Peacock in Glasgow and have remained in the field ever since.*

Q. Tell us more about your current role.

A. *I am one of three consultants based at the Scottish Pulmonary Vascular Unit. This is located in Glasgow but looks after all the patients with pulmonary hypertension in Scotland. We already do outreach clinics in Aberdeen and will soon be providing them in Edinburgh.*

Q. What inspires you in your work?

A. *Inspiration comes from three things: patients, colleagues and science. Patients because seeing them cope with day-to-day life while breathless, or having to balance taking their children to school and making up treatments, inspires me to live life to the full. Colleagues because I work with some great doctors, nurses and administration staff who actually make the unit function. And science, because trying to understand this disease and what makes it cause the narrowing of the blood vessels is how we will eventually be able to cure it.*

Q. Are any two days the same?

A. *No. I am lucky enough to have two parts to my job. I am involved in pulmonary hypertension but I also work in general respiratory covering other respiratory diseases. This keeps me very busy as I work at two different hospitals and have both acute and long-term patients to care for.*

Q. What major developments have you seen around PH?

A. *As a medical student I remember learning about pulmonary hypertension and that there was no treatment. How this has changed over such a relatively short time is amazing and testament to the fortitude of patients and their willingness to take part in clinical trials. Through this, and the incredible scientific and clinical research that has occurred, the drug treatments for patients are now much better and we see that daily in our clinics.*

›››

the*interview*

Respiratory consultant

COLIN CHURCH

> *“As a medical student I remember learning about pulmonary hypertension and that there was no treatment. How this has changed over such a relatively short time is amazing and testament to the fortitude of patients and their willingness to take part in clinical trials.”*

Q. What’s the most rewarding aspect of your job?

A. *It is of course a cliché to say the patients, but that is true. The chance to get to know patients and help them in their journey is something that makes this job truly worthwhile and exciting. Patients have incredible determination to ‘just get on with things’. In addition, having the opportunity to work with some of the best doctors I know up and down the UK is an incredible position to be in.*

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

A. *I don’t think I would single out one event as my proudest achievement as there are a number of things that I value most from my career. These are the ability to care for and meet with very interesting and brave people. In fact, the achievements which really stand out are those in which a patient has presented in a very unwell state and we as a team have managed to improve the symptoms and get them back to a better quality of life.*

Q. What excites you going forward?

A. *Being involved in pulmonary hypertension is a privilege and to work in the UK PH field is fantastic. The network of people interested in PH in the UK is very well organised, and as a group we undertake national collaborative studies with the aim of improving the treatments and wellbeing of our patients.*

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

A. *There is little doubt that treatment of this condition has gone from nothing to a lot in the space of 10-20 years. There are now a wide number of drugs which can be used to help open up the pulmonary vessels which allows me to have a greater choice when treating my patients. In addition, using more than one drug early on in the treatment has also improved outcome and symptoms.*

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

A. *I have three daughters; Erin, Isla and Clara. Between being a taxi service for trips to swimming galas or hockey matches, I don’t always get that much downtime. Saturday evenings in front of the television with the family is the best relaxation and the best fun!*

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

A. *There are two things to tell patients to help them understand more about PH: that the disease can be treated and there is great support available for patients and their carers, especially through PHA UK. To help healthcare professionals, I would tell them that this disease needs to be looked for earlier, and with more ready access to echocardiogram tests, this should hopefully allow earlier diagnosis and treatment.* ●

Research Round-up

Dan Reed looks at what happened in the world of PH research last year, and what it could mean for the future. >>>

Research Round-up

First, allow me to introduce myself. I'm Dan. I have a PhD in cardiothoracic pharmacology, and was previously a scientist at the National Heart and Lung Institute, Imperial College London. ***Some of my research was funded by the PHA UK to develop laboratory tools, using stem cells, to help understand more of the cell biology in PH.*** Part of this work included delivering presentations at some PHA UK patient events and it is a privilege to have the opportunity to work with such a special community.

As you've undoubtedly heard and read in many articles before this one, treatment options for pulmonary hypertension have advanced significantly over the past 20 years. This is a triumph of the successful collaboration between patients, caregivers, scientists, doctors, nurses, and the pharmaceutical industry (more on that later, I promise). In this article, I'm going to look back at some of the research carried out in 2017 and consider what it means for patients and caregivers.

LOOKING BACK AT 2017

Our first example takes us to decisions made on whether a new drug, which has undergone appropriate testing in clinical trials, can be used to treat PH in the UK. In February 2017, as many of you may have read, a clinical commissioning group from NHS England supported a new 'targeted' drug, called riociguat for the treatment of certain kinds of PH. Riociguat was developed based on scientists' understanding of an important molecule in the body, nitric oxide, which plays a critical role in keeping the blood vessels in the lungs healthy. In people with PH, there is not enough nitric oxide, which means the blood vessel cells in the lungs don't function normally.

Two important studies that informed how we should use riociguat were called CHEST and PATENT and were published in scientific journals including The New England Journal of Medicine, and The Lancet. Some of you may have even taken part in these studies. These studies showed that riociguat could, on average, give a 36-metre improvement in 6-minute walk distance after 12 weeks of taking the drug, or a 46-metre improvement after 16 weeks in people with CTEPH, and this improvement was maintained for around two years in most people continuing treatment. The study also showed that riociguat worked well in people who had received no other treatment and in people ho were taking endothelin-receptor blockers (like bosentan) or prostanoids (like treprostinil). This study also included scores on quality of life. The improvements in quality of life were generally positive but more mixed, and scientists and doctors are still exploring what this means.

> treatment options for pulmonary hypertension have advanced significantly over the past 20 years

Through research you may have already taken part in, the PHA UK is also working hard to understand the impact of PH on people's lives with the aim of helping people live better with the condition.

The clinical trials for riociguat were started in around 2009. This may seem like a long time ago, but when a drug is approved, it means it has passed very stringent tests and demonstrated both its effectiveness and its safety. After the European Medicines Agency has reviewed all the important evidence collected from giving the drug to patients, it goes on to be reviewed further in the UK by the National Institute of Clinical Excellence (NICE) and the NHS before it can be used.

You may have heard about the decision by the NHS not to support a new drug called selexipag, which in early 2017 underwent a further safety review by the European Medicines Agency. The data from the clinical trials for this drug does look promising but there may be some safety issues that need to be understood more fully. The fact that this drug is not available in the UK is understandably disappointing and the PHA UK is working hard to make patient voices heard in the drive to make it available (see page 13 for further information on this).

LOOKING AHEAD

Let's now think about some relevant developments in PH research which could result in tomorrow's new treatments. We have every reason to be hopeful that these studies can result in new knowledge and potential new treatments.

Some scientific developments aren't happening in a way that involves people with PH yet, but could one day give us an idea for a new targeted therapy. Examples from 2017 include polypyrimidine tract binding protein (PTBP1), which a combined group of UK, US and Canadian scientists have determined is controlled partly by a special type of genetic-like material called microRNA. When a molecule called mIR-124 is added to cells grown from PH patients, some parts of cells became non-PH like or were 'rescued' from PH, suggesting this, or drugs which act on proteins associated with PTBP1, could be a new treatment. The protein changes involved relate to a process called glycolytic flux, which is all about how our bodies use energy; which suggests energy regulation in cells could relate to PH. This study was funded by charities, but perhaps in the future, additional funding - which might include that from the pharmaceutical industry - could help convert this research, and research like it, into a new PH therapy.

Some of the most important events in the scientific and medical calendar are medical conferences. Here, informed scientists and doctors come together and talk about new scientific evidence. In some of the most important events at a medical conference, research groups at universities from around the world, as well as the pharmaceutical industry, present their newest ideas and data.

> Some of the most important events in the scientific and medical calendar are medical conferences.

This can include data from small experiments to large clinical trials, and the pharmaceutical industry does play an important role in all of these. Without input from scientists and doctors in pharmaceutical companies, we would not be able to turn small experiments into large clinical trials, which are needed for approval of new therapies.

In fact, a 'phase two' trial (so somewhere in the middle of its development) is expected to start on a new type of drug called sotatercept, which acts on a receptor called activin receptor type IIa, and can be injected under the skin just every 14 days. Activin receptor type IIa is thought to be involved in certain cell communication pathways in PH. Some early scientific data on this drug was presented at a conference in 2017 and showed that the drug could reduce the progression of lung damage in laboratory studies. So this is a good example of some early data being presented at a medical conference and this data forming the basis of potential new clinical trials.

Numerous clinical trials, including those on a new long-acting inhaled drug called QCC374, similar to selexipag, are also expected to start in 2018. This drug is too new to have a name yet. At the European Respiratory Society Conference in September 2018 in Paris, even more data on a number of new scientific ideas, early and late-stage drugs are expected to be presented - and doctors, nurses and scientists in the PH community will be in attendance to discuss any new data.

CONTINUING THE JOURNEY

We must remember that every piece of data is important – whether it is positive or negative, it allows the scientific community to better understand PH, including the treatment approaches that are likely to work, and those that are not. Scientific enquiry is a journey. Sometimes we find something useful or unexpected, and sometimes we don't and so have to change our approach. And the journey of a new idea or new drug doesn't stop there - the PH community is ready to engage in the important conversations to ensure good science makes its way through to useful treatments. ●

Clinical trials have transformed medical treatment for people with pulmonary hypertension and more patients are needed to take part in research.

Turn to p50 for details.

Young Minds

After receiving therapy to help him cope with his long-term health condition, 11-year-old *Darragh Flood* has learned to talk about his feelings. Here, his mother *Sinead* explains how helping her son seek support has benefitted the whole family too.

“Darragh was just eight when he was diagnosed with an extremely rare life-threatening condition, which leaves him in need of specialist care and 24-hour medication. The condition, primary adrenal deficiency, leaves Darragh unable to produce the life-sustaining hormone cortisol. It is life-long and there is currently no cure available, which is quite a lot for a child to come to terms with.

Initially, Darragh seemed to take everything on board but as the months rolled on, we noticed he wasn't doing so well. He was struggling to sleep, didn't like going out or playing football and was very easily upset. The more my husband and I tried to talk to him, the more he shut down. ***Eventually, exhausted and emotional, he finally opened up and we were devastated to learn how deep-seated his anxiety was.*** *He was terrified of dying and the heart-breaking thing for us, as parents, is that he had tried to cope alone. We decided he needed professional help and the psychology team at Great Ormond Street Children's Hospital arranged an immediate assessment. Darragh is under their care, so we were able to access their services.*

Darragh started therapy straight away, and we saw an instant improvement. It was quite literally life changing. Within weeks he was back playing football, seeing his friends and sleeping through the night, and he was a different child.

We were also offered family therapy sessions and we have all reaped the benefits. Darragh is more willing to explain how he is feeling, and our other children have responded by becoming more understanding, empathetic and supportive.

Darragh, now 11, is doing well and still has ad hoc sessions when he feels his anxieties growing and often asks me to arrange an appointment, unprompted.

I firmly believe that the reason Darragh's therapy is so successful is because he is so open to receiving help and embraces the various strategies recommended. He now views it as another, equally important, aspect of his health care. I really hope this doesn't change as he gets older, especially as he approaches his teenage years. If only all of society could think like Darragh does now, imagine the progress we could make in terms of changing the way people think about mental health.”

DARRAGH'S VIEW

"I like going to see my therapist as it gives me a chance to talk about my worries and I feel safe there. I know it's ok to feel a little bit worried because that's normal. But sometimes I need help to stop the worry so I go back there to feel better again. It's good to talk as it helps to work things out."

Sinead Flood is welfare manager at NewstrAid, a charity that works to benefit individuals in the retailing and distribution section of the newspaper and magazine publishing industry. ***Visit www.newstraid.org.uk or call 01279 879569.***

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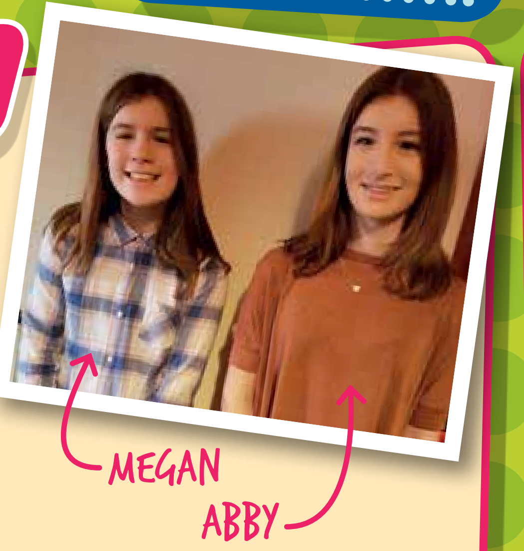
Green Leaf Crew!

GREEN LEAF CREW Q&A
ABBY & MEGAN STOTT

This issue, sisters Abby & Megan Stott from Preston take on our Green Leaf Crew Q&A together. Abby is 14 and Megan is ten, and they have two younger sisters – Matilda, six, and Lorien, three. Their dad David has PH.



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

A. Abby. *Group projects, because they're a good way to get to know people you might not usually talk to, and it's a good way to judge people's reactions to responsibility.*

Megan. *I like to do collages because it's fun to use the different materials in different ways.*

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

A. Abby. *Spend time with friends and family.*

Megan. *Relax and watch movies.*

Q. What's your favourite biscuit?

A. Abby. *Hobnob.*

Megan. *Custard creams.*

Q. What do you like to watch on TV?

A. Abby. *I don't really watch TV that often but when I do I usually watch shows like 'Impractical Jokers' or stand-up comedians.*

Megan. *I normally watch cartoons like 'The Amazing World of Gumball' but sometimes I do watch 'You've Been Framed'.*

Q. What's your favourite thing to have for tea?

A. Abby. *Roast dinner.*

Megan. *Pasta bolognese.*

Q. Who is your best friend and what do you like to do together?

A. Abby. *My best friend is Sam. We go to each other's houses a lot and mess around with music.*

Megan. *Lilly because she's always really funny and kind and always shares her things with me.*

Q. If you could meet any famous person in the world, who would it be and why?

A. Abby. *Lin- Manuel Miranda. He's a huge inspiration to me and never fails to make me smile.*

Megan. *David Attenborough because I love animals and sea creatures so I have always enjoyed his shows.*

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

A. Abby. *Shape-shifting.*

Megan. *Invisibility because it would be fun to play tricks on everyone because they couldn't see me.*

ALL 4 SISTERS TOGETHER

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

SPOT THESE THIS SPRING...

SPRING IS A GREAT TIME OF YEAR TO BE OUT IN THE GARDEN, AND IT'S WHEN ANIMALS WHICH SLEEP THROUGH THE WINTER COME OUT OF HIBERNATION. HERE ARE FOUR CREATURES TO LOOK OUT FOR IN YOUR GARDEN THIS SPRING.

QUEEN BUMBLEBEE

THE FIRST WARM DAYS OF SPRING ARE THE BEST TIME TO SPOT BEES. THEY'LL BE OUT LOOKING FOR THEIR FIRST POLLEN AND NECTAR FROM THE SPRING FLOWERS.

BUTTERFLY

IT'S EASY TO SPOT BUTTERFLIES FLUTTERING AROUND IN SEARCH OF FOOD. LIKE BUMBLEBEES, THEY'LL BE HOVERING AROUND THE PLANTS IN YOUR GARDEN LOOKING FOR POLLEN.

HEDGEHOG

THESE PRICKLY CREATURES SPEND ALL WINTER HIBERNATING, SO AS THE WEATHER WARMS UP THEY START TO REAPPEAR. YOU MIGHT FIND THEM CRAWLING THROUGH THE SOIL LOOKING FOR WORMS TO EAT.

FROG

IF YOU HAVE A POND OR WATER FEATURE IN YOUR GARDEN, THERE MIGHT BE SOME CROAKY FRIENDS WHICH CALL IT HOME. SPRING IS BREEDING TIME FOR FROGS AND TOADS.

The GREEN LEAF CREW

BY DAVID BANKS

Play your part in the **fight against PH**

Clinical trials have transformed medical treatment for people with pulmonary hypertension – and more patients are needed to take part in research.

In the UK, before a new drug can be given to patients, it must be shown to be safe and effective in clinical trials, and must be approved by the Medicines and Healthcare Products Regulatory Agency (MHRA).

Before there were therapies available to treat PH, people diagnosed with the condition had an average life expectancy of about three years. Now, thanks to the approval of various new drugs, this life expectancy is much improved.

Without clinical trials, and the patients who agreed to be involved in them, these drugs would not be available.

All of the specialist PH centres in the UK are involved in research, so you may be asked if you would like to take part in a clinical trial. If you can, please think about getting involved and playing your part in the fight against PH.

> *“I intend to continue to take part in any research, study or trial in the hope that one day we can all be cured of this disease.”*
>
> **Carole Ayrton**
> PHA UK member

Interested in taking part in clinical research?
Let your specialist centre know!

Make fundraising easy **with Just Giving**

With online fundraising now more popular than ever, *Chris Coates* explains how to get the most out of using Just Giving when you raise money for the PHA UK.

Just Giving is an online fundraising platform which was set up in 2000. Last year, £4billion was raised through Just Giving pages, making it the most popular online fundraising website in the UK. You can raise money for your own cause, or donate to a registered charity.

Just Giving also allows your sponsors to leave a personal message which allows them to show their support for your campaign. They can choose to leave their name and how much they've donated, or leave their identity and donation anonymous. This means that when people visit your page, they can read the messages of support from your sponsors, which is likely to persuade them to donate.

When you set up a page, Just Giving will give you the option of fundraising for a registered charity. This means you can set your page up to fundraise for the PHA UK and the money you raise will go directly to them, which removes the hassle of transferring the money or posting a cheque.

THREE STEPS TO MAKE THE MOST OF YOUR JUST GIVING PAGE

1 Set a target

Just Giving requires you to set a target for your fundraising. Think carefully about how much you would like to raise and make sure it's a target that you can realistically aim for. Have a look on the PHA UK Just Giving page at other fundraisers to get a better idea of what target to set for your campaign. Being able to say you've reached your target or even surpassed it is a great feeling, but don't be afraid to challenge yourself.

2 Update your supporters

A good way to boost your sponsorship is to post regular updates on your page. For example, if you are doing a half-marathon, let your supporters know how your training is going. If people know you're working hard towards your goal, they are more likely to pledge money for your cause. You can also add photos as part of your updates which is important as visitors to your page can see what you're doing.

3 Add offline donations

You might get donations directly from friends and family. Just Giving allows you to add these to your page to ensure your supporters know exactly how much you've raised. Don't forget to do this as you might reach your target earlier than you realise – allowing you to try and smash it even further! Visit www.justgiving.com to get started – setting up a page is easy if you follow the instructions set out on the site.

For a fundraising kit call **01709 761450** or email **office@phauk.org**
For more information about fundraising for the PHA UK visit **www.phauk.org/fundraising**

ME & MY JOB

Welcome to our regular column where PH professionals tell us more about themselves and their work. This issue, Sheffield-based GP **Helen Knight** shares details of her work with the PHA UK.

HOW LONG HAVE YOU BEEN WORKING IN THE HEALTHCARE FIELD? *I have been working as a GP for 16 years. Currently I work part time as a GP in a prison as well as working alongside the PHA UK.*

WHAT DOES YOUR WORK WITH THE PHA UK INVOLVE? *My work with the PHA UK involves several different strands. I am part of the PHocus2021 group to help give a perspective from primary care. I have also been working with the PHA UK to develop different ways of communicating people's stories and how we can use creative writing to help them express themselves. Another project I am involved with is developing a resource about contraception and pregnancy in pulmonary hypertension.*

WHAT'S THE BIGGEST THING YOU'VE LEARNED ABOUT THE CONDITION? *There are two things that have struck me most about pulmonary hypertension. The first is how long it can take to get a diagnosis and how frustrating this is for patients. The second thing is how advances in management of the condition mean there are increasing numbers of people with pulmonary hypertension who have a better quality of life for longer. For both these reasons, I see the need to get GPs and practice nurses more familiar with pulmonary hypertension.*

WHAT DO YOU ENJOY MOST ABOUT YOUR WORK WITH THE PHA UK? *I enjoy the varied nature of the work I do with the PHA UK. I have really enjoyed meeting members and hearing some of their stories (and the office lot aren't too bad either!)*

WHAT DO YOU LIKE TO DO OUTSIDE OF WORK? *Outside of work, I'm busy with my three kids, two unruly dogs and numerous chickens! I love baking and jam and chutney-making. I set myself a challenge each year to try a new recipe and these have ranged from angelica jam to haw ketchup!*

IF YOU HAD TO TAKE ON AN ALTERNATIVE CAREER, WHAT WOULD IT BE AND WHY? *I do sometimes wonder about working in a small tea room – I think you would get to meet a lot of people and hear a lot of life whilst clearing tables and serving tea.*

AND FINALLY... TEA OR COFFEE? *Tea, every time!*

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

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pha UK Influence.
Hope.
Integrity.

How we spend *your money...*

Source: Charity Choice (www.charitychoice.co.uk)

*Thank you to **everyone** who raises money to support the work of PHA UK. With your help, we can continue to improve the lives of those affected by pulmonary hypertension.*

And when you raise money for PHA UK, you can be confident that it's being spent in the right way. An independent assessment of our charitable activities has shown that for every £1 we spend, 96p goes on charitable activities.

For fundraising support
call the PHA UK office on **01709 761450**, or email **office@phauk.org**

In your Summer issue of Emphasis...

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

Adopting as a single parent
– Member Sonia shares her story.

Going on holiday?
– FAQs about travelling with PH.

A closer look at yoga – How it can benefit physical and mental wellbeing.

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

You can get involved in Emphasis too:

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

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

Join our PH family for free today

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Be part of a 3,500-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:

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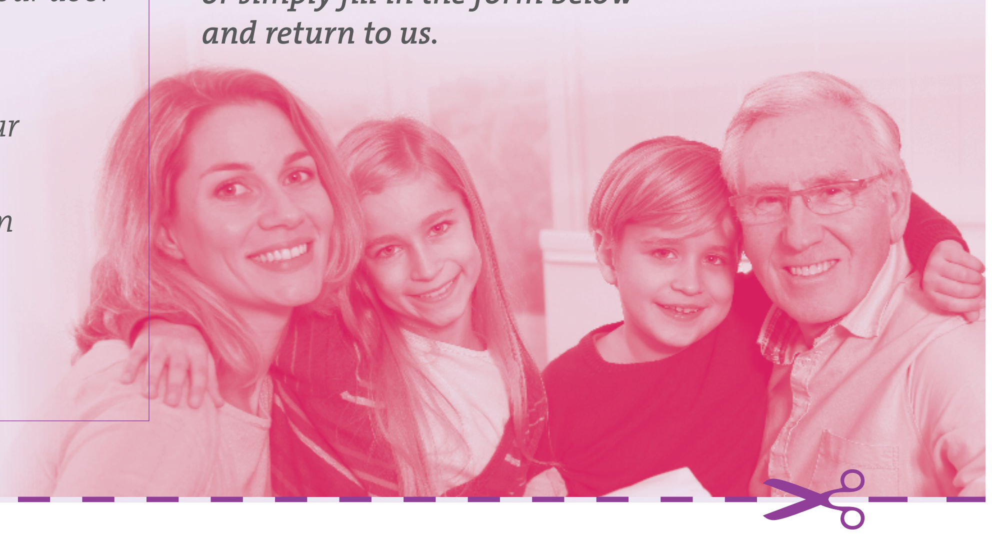
- *Helpful printed information and resources*
- *Emphasis magazine delivered to your door four times a year*
- *Free access to emotional support from qualified professionals via our partnership with **Anxiety UK***
- *Free access to financial advice from qualified professionals via our partnership with **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 3,500 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.

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Name:

Address:

Postcode:

Email: Telephone:

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

Other (please state)

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

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PHA UK
How we're structured

PHocus2021
Patient Group
Consists of 8 Patients/Carers
Steering Group
Consists of 7 PH Clinicians, Primary Care Practitioners, Academia Representatives, Executive Trustee

STRATEGIC PARTNERSHIPS
Anxiety UK
Turn2us

EXECUTIVE TRUSTEES
Iain Armstrong
Chairman
Kay Yeowart
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

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

PHA UK Contact Details

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Unit 1, Newton Business Centre, Newton Chambers Road,
Thorncliffe Park, Chapeltown, Sheffield, S35 2PH
Registered Charity Number: 1120756

Anxiety UK

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

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