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PWS news

Issue number 159 | Spring 2024 | ISSN 0263-449X | Reg. Charity No. 1155846

Awareness Month is coming!

Find out what we've got lined up and how YOU can get involved!

PLUS!

ALL THE LATEST NEWS
SUPPORT | FUNDRAISING

PWSA UK
PRADER-WILLI SYNDROME ASSOCIATION UK

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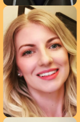

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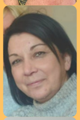

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Welcome to your PWS News!

As you may have noticed, your PWS News has been given a bit of a makeover, with a fresh new look and some exciting new features.

With May just around the corner, our focus in this edition is on previewing what we've got lined up for Awareness Month, including details of an exciting new collaboration and a truly spectacular way to mark Go Orange Day!

Other features this quarter include a celebration of our amazing volunteers, and the first of a series of profiles on our trustees, starting with our Chair, Danny Leslie, as well as your regular support and fundraising sections.

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Important - about your magazine

Apart from a very small number of printed copies for those unable to access other formats, this is the first primarily digital edition of PWS News. Also, as you know, this magazine was previously included as part of our paid membership offer. We have now switched to free membership in order to make it accessible to all, so if you have opted to continue paying your membership fee in the form of a monthly, quarterly or annual donation then we would like to take this opportunity to thank you for your continued support. It really does make a difference!

Inside this issue...

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Follow us

May is PWS Awareness Month!

PWS Awareness Month, as its name suggests, is all about raising awareness of the condition as widely as possible, as well as raising valuable funds to help improve the lives of those living with it. This year, we're doing something a little different, but our vision remains the same: to overcome the challenges of life with PWS

How it works...

We have an action-packed Awareness Month planned, with opportunities for everyone in our amazing PWS community to get involved.

Also, in addition to an exciting collaboration, we have a truly spectacular way to round off the month!

The diagram on the right shows the three elements that make up our campaign.

Find out more about what we're doing and how you can take part on the next few pages!

PWS Awareness Month

A globally recognised campaign covering the whole of May

Move it May

Our physical activity challenge element of Awareness Month

Glow Orange

Taking place on Friday 31st May - Go Orange Day

Awareness Month preview

Working together for a better future for our PWS community

Awareness Month is the perfect time for the launch of PWS Stronger Together, an exciting new partnership between PWSA UK and the Foundation for Prader-Willi Research (FPWR) UK.

Why are we working together?

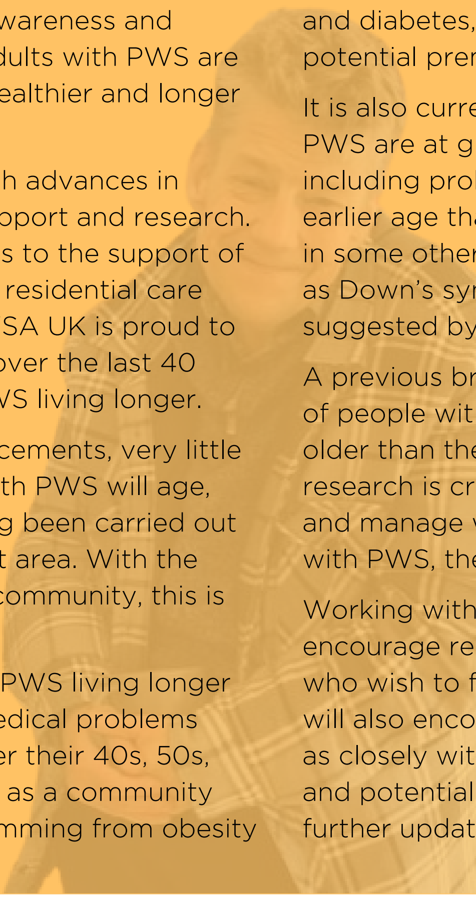
We know that by working together, our two organisations will be able to achieve more, particularly in the field of research. We want to ensure the effective use of limited resources to further knowledge and understanding of PWS and support all those impacted by PWS in the UK.

While both charities will continue to operate independently, we are joining forces for this specific initiative.

This year, our two charities have joined forces to raise awareness and funds for research into ageing in PWS as part of our Awareness Month activities. However, we will continue to work in partnership on wider research and awareness projects at other times of the year too.

PWS Stronger Together has launched a joint website at www.pwsstrongertogether.co.uk and a dedicated email address at info@pwsstrongertogether.co.uk.

Why do we need research into ageing in PWS?



With greater understanding, awareness and management of PWS, many adults with PWS are leading meaningful, fulfilling, healthier and longer lives.

This has been achieved through advances in medical interventions, care, support and research. It has also been possible thanks to the support of families, people with PWS and residential care providers – and, of course, PWSA UK is proud to have played a significant role over the last 40 years in seeing people with PWS living longer.

However, despite these advancements, very little is known about how people with PWS will age, with little to no research having been carried out into this increasingly important area. With the help and support of the PWS community, this is hopefully about to change!

As the number of people with PWS living longer increases, it is unclear what medical problems people might face as they enter their 40s, 50s, 60s and beyond. For example, as a community we may see complications stemming from obesity and diabetes, increased risk of heart disease and potential premature aging.

It is also currently unknown whether people with PWS are at greater risk of developing dementia, including problems with worsening memory at an earlier age than the general population, as is seen in some other neurodevelopmental disorders such as Down's syndrome, though this has been suggested by some small studies in PWS.

A previous brain scan study found that the brains of people with PWS, even in their 20s, appeared older than their actual age. Therefore, the need for research is crucial if we are to prepare, understand and manage what the future might hold for some with PWS, their families and the PWS community.

Working with FPWR UK, we are determined to encourage research and work closely with others who wish to fund and carry out this research. We will also encourage our PWS community to work as closely with researchers as possible from the UK and potentially further afield. Please look out for further updates as we receive them!

Move it May: how YOU can get involved!

Get ready to get fit, be healthy, and make a difference this May with our exciting campaign, Move it May!

Our goal for Move it May is simple:

- **To bring our communities together across the UK to promote health and wellness**
- **To shine a spotlight on Prader-Willi syndrome**
- **To raise funds towards research into ageing in PWS.**

By taking part in any kind of physical activity, each step (or any form of movement) will help move us all around the UK (virtually).

On 31st May, which is Go Orange Day - or, as we are rebranding it this year: Glow Orange - key landmarks across the UK will light up in orange (in real life!) to mark our progress!

Participating in Move it May is simple and fun! Whatever your preferred form of movement and whatever your ability, there's a way for everyone to get involved. Here's how you can participate:

1. Decide how you will move in May and who you'll being doing it with - let your imaginations run wild!
2. Use the World Walking app to log your activity and track your progress towards your goal. Watch as your efforts contribute to lighting up venues across the UK in orange!
3. Spread the word on social media using the hashtag #MoveitMayforPWS and encourage others to join in.

Please remember to tag:

Prader-Willi Syndrome Association UK

- Facebook.com/PWSAUK
- Twitter.com/PWSAUK - @pwsauk
- Instagram.com/PWSAUK @pwsauk
- Linkedin.com/company/pwsauk

Foundation for Prader-Willi Research UK

- Facebook.com/FPWRUK
- Twitter.com/FPWRUK - @fpwruk
- Instagram.com/foundationforpraderwilliuk
- TikTok.com/@fpwruk

Our Move it May route

Follow our progress around this route throughout May via the World Walking app and through our own social media updates - and on 31st May, each landmark we pass (plus Moorish Castle, Gibraltar, which isn't on the route) will light up in orange. More information on Glow Orange and how to use the World Walking app can be found over the page!

Continues >>>

Awareness Month preview

Glow Orange

On the evening of Friday 31st May, all the buildings that you have 'virtually' walked by during Move it May for PWS, will light up orange to show their support. If one of the buildings, castles or bridges is close to you, we would love it if you can pop along and capture some pictures. Don't forget to wear something orange yourself. Again, if you are happy to do so, please post your pictures/videos to social media and tag in both PWSA UK and FPWR UK, using the social media handles on the previous page and the hashtag #GlowOrangeforPWS.

The locations lighting up orange:

- Spinnaker Tower – Portsmouth
- Bridport Tower Clock
- Trowbridge Civic Centre
- Bristol City Hall
- Cardiff Castle
- Swansea Guild Hall
- Worcester Guild Hall
- Old Joe – Birmingham University campus
- The Mersey Gateway Bridge
- Belfast Castle
- Ranfurly House, Dungannon
- The Burnavon, Cookstown
- The Bridewell, Magherafelt
- Hamilton Town House
- Caird Hall – Dundee
- Camera Obscura and World of Illusions – Edinburgh
- Millennium Bridge – Newcastle
- Penshaw Monument – Penshaw, Tyne and Wear
- Middlesbrough Town Hall and City lights
- Darlington Hippodrome
- Bradford City Hall
- The Merrion House – Leeds
- York City Walls
- C4DI building – Hull
- Trinity Arts Centre – Gainsborough
- Green's Windmill and Science Centre – Nottingham
- Nottingham Council House
- St Edmundsbury Cathedral – Bury Saint Edmunds
- Southend Civic Centre
- Battersea Power Station
- Moorish Castle. Gibraltar (not on route)

How to use the World Walking app

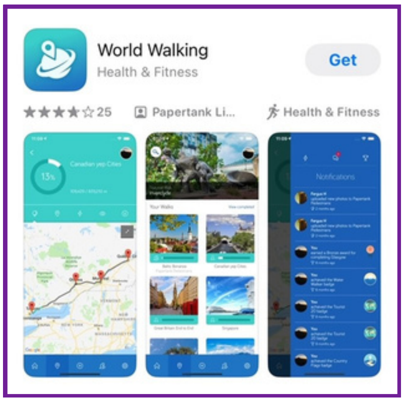
1. Go to https://worldwalking.org/
2. If you have used the website before then log in
3. If you are new to the website, then please register for free.
4. Once you have logged in/joined, please paste the following link into your browser - https://worldwalking.org/groups/p9098
5. Once you have joined the group, go to the My Walks page on your dashboard (on the website) where you will find the group's 'Move it May for PWS' walk. Click and join the walk.
6. This group walk will take you round the UK via all the landmarks who have agreed to 'Glow Orange' for us on the 31st May.
7. Please note the walk starts on the 1st May.

Continues >>>

Awareness Month preview

Using the World Walking iOS app

- Complete steps 1-6 from the previous page on the website – this is due to it being a private walk that won't show in the General 'Walk' category.
- Download the World Walking app from the App Store or Google Play. This is what it looks like in the app store:



- Login using the same login that you created for the website.
- Once logged in, click on the second button from the left at the bottom of the tabs (looks like an upside-down egg with a circle in it)
- This will bring you to 'Your Walks' page and will show the 'Move it May for PWS' icon – see image below:

How to add your steps

1. Manually – you can enter your steps manually on both the website and IOS app by using the 'Bank steps' button.

a. On the website home page in the section 'Your Bank' simply click on 'Add Steps' – this will take you through to a new page where you can add in your steps. (please ensure the tab at the top is in steps)

b. On the IOS app from the home page click on the middle icon at the bottom of the app (circle with a + sign), this will take you through to a new page and you then just click on the same symbol again (circle with a + sign) and add your steps.

2. Via an app such as Fitbit/Apple Health Kit

a. To connect your Fitbit device to World Walking via the website or app, click on Settings and then click on Apps on the menu that appears.

b. In the Other Apps section you will find a Connect to Fitbit button. Just click it to connect your device with World Walking.

c. When you do that the fitbit.com webpage will open and you may be asked to log in to your fitbit.com account. Enter your fitbit.com email address and password then tap "Login". Next, tap "Allow All" to provide World Walking with your activity information, then tap "Allow". You'll be taken back to the World Walking website/app and your Fitbit steps will sync from then on.

d. To sync your Health Kit with World Walking you must first of all enable HealthKit by logging into the World Walking app, clicking on 'Apps' and then activating Health Kit. Once you have done that, you can verify World Walking is connected to HealthKit by opening the 'Settings' app on your iPhone, then going to 'Privacy' and then 'Health' and making sure the check beside Steps is enabled.

e. Once enabled, the next time you open the World Walking app it will automatically bank any steps recorded through Health Kit since you last used the app.

How to use banked steps on the 'Move it May for PWS' walk

You will be able to see your 'banked' steps on the website and iOS homepage. Once you have built up a bank of steps, you can spend this on the 'Move it May for PWS' walk (note: to do this you will have had to have joined the walk)

a. On the website, click on Dashboard then click on 'Spend steps' – a window will appear that will show the 'Move it May for PWS' icon. Click the arrow on the right – this will take you through to the next page, from here click on the blue circle and drag it to the right – as you drag it you will see the number in the 'Spend' box go up. Once you have spent all your steps, click on the bottom icon 'Spend distance on walk'

b. On the app from the homepage, click on 'Steps banked', from here click on the blue circle and drag it to the right – as you drag it you will see the number in the bubble above the blue circle go up. Once you have spent all your steps, click on add. A window will pop up asking you to confirm you want to spend all your steps on the 'Move it May for PWS' walk. Click yes.

How to convert exercise to steps

- Here is an easy exercise converter for you to use - https://movespring.com/resources/activity-converter
- Example – I did a 30-minute freestyle (breaststroke) swim – using the table. I can see that for every 1 minute I swim it is the equivalent of 181 steps so 30 x 181 = 5,430 steps
- 20 mins of movement (not walking) is the equivalent of walking 1 mile which when converted into steps for our walk is the equivalent of 2,000 steps

Alternatively, just email Karen at kwilkinson@pwsa.co.uk with your steps or distance and she will add it to our total!

Next PWSA UK town hall meeting

The next meeting will take place on Tuesday 23rd April 2024 at 7.30pm. This is a chance to meet with Chair of Trustees Danny Leslie and CEO Jackie Lodge.

The meeting will take place virtually via Zoom and is an opportunity for us to engage with and listen to our members in order to shape the strategic direction of the Association.

At the last meeting in October, we set out the main priorities:

Reaching all parts of PWS community
- Including the four nations and all regions
- Ethnic minority communities

Adults with PWS
- Listening and acting (an example being the recent launch of the Sunflower lanyard)
- Residential standards (Quality of Life)
- Developing the section for adults on our website and our Wise Owl Feathers newsletter

Securing financial stability
- Diversifying income
- Telling our story

Partnerships and synergies
- PWS community, working with the Foundation for Prader-Willi Research and IPWSO
- Being a stronger voice for PWS community

At the meeting in April we will look at three topics in some detail and one of these will be longer term planning for adults with PWS.

We want to hear what other topics and issues you would like to raise with us! Please email jlodge@pwsa.co.uk.

UK PWS charities meet with Soleno

PWSA UK and the Foundation for Prader-Willi Research (FPWR UK) recently met with Soleno Therapeutics, the company behind DCCR.

It was wonderful to talk with Soleno about steps to have drugs approved in the UK. Whilst this process will take time, we were able to discuss and note some important things we can start to do now to pave the way for any future approved medicines.

It was also good to chat about other related and important issues such as raising the profile of PWS and the importance of the PWS community working together to spread awareness and understanding of life with PWS.

Both charities were very grateful for Soleno's time and look forward to all working together on this going forward. We wlll share further updates as and when we receive them!

Did you know?

The missing portion in our feather logo represents the missing genes on the 15th chromosome. Our feather logo, though missing something small, is vibrant, unique and full of life – just like those with PWS!

News

SAVE THE DATE: Parent conferences 2024

We have two conferences for parents coming up this year:

- 22nd June - virtual conference for parents of over-16s
- 12th October - face-to-face conference for parents of under-16s at Chilworth Manor Hotel, Southampton

Full details to come - in the meantime, please email Sheila at sinwards@pwsa.co.uk to find out more.

Shop online, support PWSA UK!

Did you know that you can support PWSA UK by shopping online?

Easyfundraising has partnered with more than 7,000 big brands so that whenever someone shops online with any of those names via the easyfundraising website or app, those brands will make a donation to a charity of your choice at no extra cost to you! PWSA UK is one of the charities registered with this initiative so we will benefit when you shop with any of those brands. Find out more and sign up at www.easyfundraising.org.uk.

Thank you - these things really do make a different to small charities such as ours!

Community events in July - and WalkOvers with a twist!

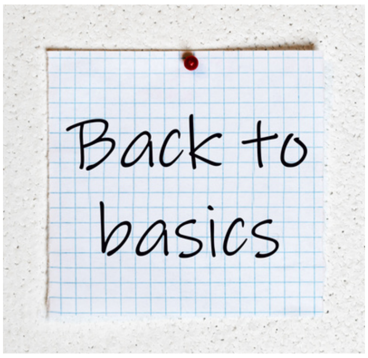
Booking is now open for our community events in July:

- 14th July - Hastings WalkOver and community day
- 21st July - Nene Park WalkOver and community day
- 28th July - Waterways Farm Outdoor Classroom community day

This year, for the WalkOvers, we are introducing some fun activities to the day and encouraging everyone to bring a picnic and spend some time with us – you don’t have to do the walk, but if you do, you’ll get one of our amazing medals to keep. Come and join us for the afternoon and celebrate our unique and mighty community!

To reserve your free places at any of these events, please go to pwsa.co.uk/events where you can find Eventbrite links with further details and booking information.

Going back to basics - part 2



Welcome to the support section for the spring magazine.

Firstly, thank you for all the positive comments we have received about the last magazine. It is great to know the subjects we have chosen have been helpful. Carrying on with our 'back to basics' focus, this edition is going to be looking at hypotonia, sleep problems, blame shifting and storytelling.

If you are experiencing issues with any of these subjects (or, indeed, anything else relating to PWS) then please remember you can contact us, even if just for a chat. Remember, a problem shared is a problem halved.

Hypotonia in PWS

by Patsy Lecont
PWS Specialist Team Manager

What is hypotonia?

When we talk about hypotonia, we are referring to the low muscle tone that all those born with PWS have – it simply means their muscles are not as strong. Their muscle size is exactly the same, but is made up of far more fat cells than muscle cells.

What does that mean for those with PWS?

You may recognise the poor muscle tone as your baby being quite floppy, or needing to be fed by NG tube (due to unsafe swallow). It takes an incredible 43 muscles to work in co-ordination to be able to swallow and breathe at the same time. You may see your child or young person finding it difficult to navigate stairs, kerbs and uneven ground. Hypotonia doesn't just affect the major muscles that we think of – it affects every muscle within the body. For some, this will be greater than for others-as with most things with PWS, it can vary from one person to the next.

So let's look at how this causes difficulties. Development milestones, such as supporting their own head, sitting and walking can all be quite significantly delayed and this is perfectly normal. Most of those with PWS will have an unsteady gait (the pattern in which they walk) and this is why we always recommend, when filling in benefit forms such as DLA or PIP, that you mark virtually unable to walk. Without getting too in depth, the definition of walking means a bend in the knee with a foot pattern of heel to toe – this very rarely happens in those with PWS. Their gait pattern tends to be more of a shuffle or side to side motion.

It is rarely forward propelling, and it's because of the muscles around the hip and pelvis. The low tone means that the muscles have a hard time engaging and supporting those areas. The same applies for scoliosis – the muscles that run up the sides of our spines are weak, and cannot always hold the spine in the right position.

Is your child or young person a mouth breather? This can also be attributed to low muscle tone. You may find your son or daughter is a shallow breather (rarely taking closed mouth deep breaths), and again this is due to the low muscle tone.

So what's the good news, right? Well, we know that this low muscle tone improves significantly with growth hormone treatment, and can improve with age. Although the muscle tone will always be low, it won't be as severe as at birth and there are plenty of people with PWS who take part in trampolining and swimming competitions, take part in races and have climbed the 02 to name but a few!

We are a small but incredibly mighty community!

Sleep problems in PWS

by Ruth Consterdine
PWS Specialist Team Deputy Manager

Many individuals with PWS will experience sleep disturbance and the most common of these is excessive daytime sleepiness (EDS) which can be related to sleep apnoea.

There are two types of sleep apnoea. The first is known as obstructive sleep apnoea (OSA), and is linked to increased BMI or body mass index. The second is central sleep apnoea (CSA), a disorder meaning that an individual pauses breathing while asleep.

A certain number of these apnoeic pauses are normal in all infants, children and young people. However, in individuals diagnosed with CSA, these apnoeas are usually longer and more frequent. CSA occurs when the brain does not send the correct signals to the muscles that control breathing.

Sleep apnoea and growth hormone

It is usual for children to have a sleep study before growth hormone (GH) treatment is given as it may cause tonsils to grow, which can worsen obstructive sleep apnoea.

However, studies have shown that most patients had better sleep with less apnoeas after six weeks of GH therapy. Medical literature demonstrates that GH therapy can improve respiratory function, physical performance and bone mineral density. There is also evidence to show that cognitive ability is improved in both children and adults.

Daytime sleepiness is also a feature of PWS and it seems to overtake the person very easily, particularly when in a situation they do not like or if they are bored. You can almost guarantee as soon as a journey in a car, train, bus etc starts they will be asleep.

It may be that a child will require an extra rest break at school to allow for them to sleep. This means they are ready to start learning again rather than feeling sleepy the whole time. Sleepiness can also lead to behavioural issues so it is important for those in education or care are aware of this and take into consideration what they are expecting of them.

Individuals with PWS have more sleep cycles per night and more REM periods (dream sleep), which means the amount of REM sleep is decreased. This reduces the amount of total sleep they have each day, putting them in what the Prader-Willi Syndrome Association USA refers to as 'sleep debt'.

The excessive daytime sleepiness has been connected to the intrusion of rapid eye movement (REM) sleep into wakefulness. Due to this people with PWS may appear to have narcolepsy like symptoms.

The treatment of excessive daytime sleepiness and narcolepsy are similar. The first intervention to improve sleep hygiene is to have a good night time routine to assure the appropriate amount of sleep and to supplement this with planned naps, if necessary. The second intervention is to treat the source of sleep disruption; CPAP or BIPAP are needed for obstructive sleep apnoea or intermittent hypoxemia.

Finally, it is important to remember if your child or adult with PWS's sleep pattern changes, they should be checked by a doctor. They may have developed sleep apnoea or other breathing issues that need medical support.

CPAP machine

Blame shifting and storytelling

by Sheila Inwards
PWS Specialist Advisor

Like many of the characteristics of PWS, blame shifting and story telling, also known as confabulation, can be misunderstood. It can so often be seen as lying - however, this isn't what is happening.

When an adult or child do either of these, it is their interpretation of a situation. If it is around food stealing they will deny everything even when confronted with the evidence. We know how important it is to them to please people and especially their family. When the syndrome wins, they can feel ashamed and worried you think less of them. With this in mind, it is important we can differentiate between issues that need addressing and ones we can put aside, at the same time letting them know we know the truth.

Everyone supporting someone with PWS is under pressure to ensure food is out of sight at home but, in the community, it can be harder. You don't only need eyes in the back of your head but literally all round your head. It can feel an overwhelming task, but we can only do the best we can. This is the same for the person with PWS - they can only resist food for so long if it is within their grasp. So, you can understand if they give in, how frustrated they are with themselves and can get to the point of not liking themselves, leaving them worried you will feel the same.

This is when the blame shifting and story telling can happen. They might blame you or another family member in a way that they are not blaming them for eating the item, but rather they blame someone for letting them access the food. None of us are at fault - we are doing our best, so in this situation again you would let them know you know the truth without saying to them they stole the food. It can be easier said than done when involved in the situation, but is worth following this strategy for everyone involved.

I think we all know what wonderful hearing they have - however, what they hear and how they report it can be vastly different. If they hear their name mentioned in a conversation between other people, their instinct is to assume they have done something wrong, or the people do not like them. Whereas, in fact, it could be a brother telling their mum how good they had been, or parents talking about a family event and just mentioning their names. They instantly think they are in trouble, and when asked why they are upset, the story will sound feasible. Their reply can turn into a wonderful piece of fiction that is hard to imagine

Continues >>>

they are capable of making up.

One example of storytelling is when two 18-year-old men were taken on a long journey from the south coast to Derbyshire. On the way, they witnessed a motorbike accident and saw an ambulance, police officers and a motorbike in the middle of the road. By the time they got to Derbyshire, they continued to tell the person they were meeting they had seen a motor bike accident, the cyclist was taken in an ambulance to London hospital but they couldn't help him so he had to go in a helicopter to another hospital. It continued with all the blood and gore they saw and all the serious injuries. The lady asked if they witnessed all of that, and they both said yes! Mum stepped in and said they saw the bike and ambulance, without correcting them, and the other lady understood exactly what had happened.

Another example is one young man who was found by his school to have a large bruise on his arm. When questioned, he said his mum did it. Naturally, mum was approached and at this point explained she had taken him to the doctors for an injection which had caused a large bruise.

Thankfully, the school were sensible and took on board what had happened. This isn't always the way, and this is why anyone looking after someone with PWS is aware of confabulation, ensuring they don't jump to the wrong conclusion.

To sum up, it is:

- Important to distinguish between harmless imaginative stories and what is real.
- Important to let them know that you know the truth.

Meet our PWS specialist team!

We're here to help you - call 01332 365676 or email supportteam@pwsa.co.uk

Meet the trustees

Each quarter, we will be profiling a different trustee, starting with our Chair, Danny Leslie

Danny Leslie

Danny has been a trustee since November 2016, joining less than a year after his son, Albert, was born and subsequently diagnosed with Prader-Willi syndrome.

He is married to Rebecca and they have six children – Albert, Alice, Florence, Jacob, Matthew and Caitlin.

Danny is a serving officer in the Armed Forces having been Commissioned into the Royal Electrical and Mechanical Engineers from the Royal Military Academy Sandhurst in April 2003.

Why did you want to become a trustee?
Like many careers, being in the Army can be very tough. You need immense levels of support to be able to deliver what is being asked of you. However, it is also immensely rewarding because you have the unquestionable support of those around you and your sole purpose is to serve and support them. My family has always supported me in my career but, when Albert was born, I felt lost in how I could support them. PWSA UK offered an avenue of support that struck at my own desire to support and serve others. That desire led me to want to serve the Association and wider community in any way I could, and that led me to answering the advertisement for trustees. I wanted to make a difference to the community, just like they had for me.

What difference do you feel PWSA UK has made to your family's lives, including in the early stages following diagnosis?
Ultimately, it is that feeling that you are not alone. That whatever PWS throws at you, there is an avenue of support. PWSA cannot change the challenges we face but, they can and do support us through it when we need it. In the early stages that feeling of not being alone was very important so, family events were a great source of comfort. As Albert has grown older, knowing there is a voice of experience that can support when needed over things such as DLA, EHCP, etc has become more important. As I said though, the most important aspect is not being alone because facing PWS can feel a very lonely place, even when surrounded by family and friends.

Danny with son Albert

Is there anything you know now about PWS that you wish someone had told you at the beginning of your PWS journey? What advice would you offer to someone beginning theirs?
That is quite difficult as every day is a learning day. There are so many things that I wish were different, that I had done differently, or knew about given the benefit of hindsight. So, I suppose, my main advice to people would be to not be a victim of what might have been if you knew something more or something different had happened. Do not look back, take encouragement and pride that despite the adversity you have and will face, you continue to move forward and will also be a beacon of support for others to move forward.

Meet the trustees

How do you feel your own life experiences, including your military career, have influenced the work as Chair of Trustees?
As has already been touched on, my day-to-day life in the Army is about serving others. I see my role as setting the conditions for others to achieve their best. The Army has also developed my ability to plan for the long-term, recognising that in each individual success or failure there is a bigger picture that they serve to achieve.

It has also given me the ability to adapt my plan for the bigger picture as circumstances change. My wider life experience is similar in that it has shown me there is never a single golden goose egg that will resolve a situation in its entirety on its own. Therefore, my approach as Chair has been to keep moving toward the long-term with good plans that can be adapted as we go and in so doing, setting the conditions so that others can achieve their best.

What do you feel are the biggest challenges currently facing our PWS community?
Being alone. There is so much going on in the world from economic gloom, through pandemic to war. It is all frightening and on top of that we face the behemoth that is PWS. That feeling of fear and helplessness can be a very lonely place, we have all been there and continue to face it.

What would you like to see the Association achieve in the future?
The role of any charity should be to do so well it is no longer needed. That is the nirvana. PWSA does a simply brilliant job of supporting people when they need it most. I would like to see those calls for help reducing as that means we are moving to the nirvana. I can assure our community that we are working as hard as we can to get there.

What would you say is the best thing about being part of our PWS community?
That we understand.

Do you have a message for the community?
You are not alone. Whatever you face, no matter how hard the difficult times are or how good the special moments are; PWSA, the wider community and I am stood at your shoulder ready to support you. All of us are just a phone call, message or conversation away from sharing your pain and joy. We may or may not be able to resolve individual battles but, in serving each other through support, we may just set the conditions to achieve our best in the war.

Celebrating our brilliant PWSA UK volunteers

by Wendy Thomas

Volunteer Development Officer at PWSA UK

Having joined the team at PWSA UK at the start of this year to look at volunteering within the organisation, I have been inspired and impressed by our amazing volunteers and the vital role they play in supporting the PWSA community across the UK. PWSA UK volunteers provide support in a wide range of roles and ways; bringing a breadth of skills, expertise, and experience to the organisation that we would not be able to replicate otherwise.

This is a snapshot of the many ways our PWSA UK volunteers enhanced what we were able to offer in 2023:

- Over 200 people took part in fundraising events for us including the Great North Run, Scafell Pike, the London Marathon and Parallel Windsor, raising over £100,000. We literally couldn't operate without your incredible contribution!
- By facilitating over 12 parent to parent groups over Zoom, providing valuable parent to parent support across the range of age groups from birth to adulthood. These groups are facilitated by parent volunteers, in partnership with a member of our team, providing support, information and a shared, safe place to meet and talk. If you have joined one of our P2P groups, you will be aware of the role our volunteer parents play in facilitating and leading these groups, sharing their lived experience, and building networks.
- Seven community events delivered across the UK, attended by 270-plus members of the community, including the Hastings Walkover, Community Days at Blair Drummond and Waterways Farm, and the Community Weekend at Sandy Balls.
- Hosting parties that were attended by 150-plus children, young people and adults with PWS, where they could meet with old friends and make new friends, across the UK reaching from the West Country to Scotland and many places in between! Without the enthusiasm and dedication of our volunteers many of these events would not be possible.

We are fortunate to have the help and support of volunteers who support our work through their specialist skills and networks. Whether this is helping us with our brand, retail design or developing a new website – our work is enhanced by our network of volunteers. The board of trustees of PWSA UK are all volunteers and give of their time, experience and expertise to support the work of the Association.

Put simply – we could not do what we do without the generous help of so many.

A huge thank you to everyone that has been a part of the amazing volunteer story within PWSA UK so far.

We are now looking at how we can build on these successes and the invaluable roles volunteers play in a small organisation like PWSA UK. In uncovering the wealth of experience and skills that are held within our PWSA membership group alone there are possibilities for new and exciting volunteering opportunities to expand our offer of support and training. I have been touched by the willingness expressed by parents in the P2P groups I have attended to give of themselves and their time to support others with a shared, lived experience.

Volunteering doesn't need to be a huge undertaking to make a difference; being able to give a day a year, a regular monthly commitment, or an hour here and there all adds up and helps us to build a strong and thriving PWSA UK community.

Over the coming weeks and months, we will be sharing stories of the wonderful contribution our volunteers make and new ways of building on and developing this partnership. If you would like to know more about how you could get involved, please complete the expression of interest form on the PWSA UK website or email me at wthomas@pwsa.co.uk.

Fundraising

Hello!

Well, spring is definitely on the way along with lots of exciting events for you, our wonderful community, to take part in.

Karen

Lizzie

London Marathon

While the Marathon itself is obviously fully booked, there is still chance for you to come along and join us on Sunday 21st April, when will be at mile 20 cheering on our 8 runners. If you are able to come and join Jackie and Karen, it would be great to have you with us. We are hoping that it is not going to rain this year, but it didn't dampen our enthusiasm last year. It is a great event and a real spectacle so if you want to come and join us please email Karen on Kwilkinson@pwsa.co.uk and she can send you details of how to get to us and where we are.

Parallel Windsor

This takes place at Windsor Castle on 7th July. Last year was the inaugural event and this year it is going to be even bigger and better. This event is open to people of all abilities: walk, push or run - there are no cut off times.

Everybody who starts gets a medal, T-shirt and goody bag and you can choose from: 100m, 1K, 5K, 10K or their very own SuperSensory 1K. This is a fantastic event, so please let us know if you'd like to take part!

Babble Ride Across Britain

Looking for the challenge of a lifetime?

Across 9 epic days from 7th to 15th September, Babble Ride Across Britain covers 980 miles of the most beautiful and scenic landscapes accessible on two wheels. There is no better way to travel from Land's End to John O'Groats!

Since 2009, RAB has enabled thousands of riders to experience the magic of cycling end-to-end of the UK, as well as raising millions of pounds for charity.

Fancy taking part? Drop us an email to find out more!

Andy's epic cycle challenge!

A huge thank you and good luck to Andy Morrell, who is busy training ahead of cycling from Land's End to John O'Groats this year to raise funds for PWSA UK.

We wish him all the very best, whichever way round he is doing it. Andy is a friend of Jack who has PWS - and it sounds like Jack is getting involved in supporting Andy!

Andy told us: "I've been out a few times and am trying to complete 100 miles a week at the moment, but the weather has not been particularly nice for training in!

"I'm going to try and complete a 100-mile ride before the end of the month, which will give me a gauge of where I am at!"

All the best, Andy – and we will share an update on how the big Land's End to John O'Groats challenge goes once he has completed it!

Dry January brings fundraising cheer for PWSA UK

Lauren Pemberton and her partner decided to raise funds for PWSA UK by taking part in Dry January. They managed to raise an impressive total of £420, in addition to feeling much healthier and saving some money! Thank you and well done both!

Thank you, Toyota!

A huge thank you to Toyota Manufacturing UK Charitable Trust for the generous donation of £1,824 for two PWS community events to take place in the Deeside area of Wales.

Also, thank you to Helen and daughter Whitney who attended the presentation at Toyota's Deeside plant to receive the donation on PWSA UK's behalf.

Fundraising

New merchandise!

We have been busy behind the scenes developing new merchandise. Why, you may ask? Supporting the association by purchasing merchandise helps us in more ways than one. Firstly, profits from sales are reinvested directly to fund the work we do. And, by wearing our items, you are raising awareness for us and PWS.

We wanted our new merchandise to be wearable and suitable for everyday use. We worked closely with Kerry, who designed our logo. His team brought our ideas to life and helped us explore new ways to incorporate our feather motif.

The favourite tote bag is back and improved, with added structure and more room. The hoodies and T-shirts feature a more subtle design, ensuring they are versatile for everyday wear. We've also introduced an expanded sizing range from XS to XXXL.

Caps have always been popular, but this time we wanted to introduce something different—a beanie. While the weather is warming up, we hope this will become a staple for the cooler months.

And finally, the teddy bears. Another favourite... we believe their cuteness speaks for itself!

To purchase any of these items, please visit our online shop at

pwsa-uk.ecwid.com

Events calendar

For the most up to date information, including who to contact for each event, please visit pwsa.co.uk/events

May

4 - Tottenham Skywalk.
10-14 - PWS Community Weekend at Sundrum Castle, Scotland.
11 - PWS Community Day at Ayr Beach, Scotland.
17-20 - PWS Community Weekend at Southview Holiday Park, Skegness.
18 - PWS Community Day at Natureland Seal Sanctuary, Skegness.
31 - Go Orange for PWS Day.


May 4 - Tottenham Skywalk

June

13 - Parent to parent support group for parents of children aged 8-16, on Zoom at 8.30pm.
20 - Parent to parent support group for parents of children aged 3-8, on Zoom at 8pm.
22 - Parents' conference (for parents of over-16s).
23 – Skydive, Langar Airfield.

July

7 - Parallel Windsor.
14 - PWS Summer Community Day at Hastings, 11am-2pm.
21 - PWS Summer Community Day at Nene Park, 11am-2pm.
28 - PWS Summer Community Day at Waterways Farm.

August

Details of events TBC.

September

7-15 - Ride Across Britain. Cycle from Land's End to John O'Groats.
8 – Great North Run.
20-23 - PWS Community Weekend at Sandford Holiday Park, Dorset.
21 - PWS Community Day at Studland Beach, Dorset.

October

12 - Face to face conference in Southampton for parents of under-16s.
14 - Parent to parent support group for parents of children aged 3-8, on Zoom at 8pm.
17 - Parent to parent support group for parents of children aged 8-16, on Zoom at 8.30pm.

November

Details of events TBC.

December

Details of events TBC.

July 7 - Parallel Windsor