

PWS NEWS

Summer 2024

Issue no. 160

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PWS Updates and Much More!

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What's inside

- 03** **Welcome**
Welcome from Jackie
- 04** **Awareness Month**
Recap of our biggest Awareness Month ever
- 05** **Research**
The latest updates on research and PWS Stronger Together
- 06** **Transitions**
An article from Patsy focusing on transitions through school
- 08** **CAMHS**
Specialist Prader-Willi Syndrome (PWS) Service, Maudsley Hospital, London

- 10** **Fundraising**
Updates from Karen on all of our wonderful fundraisers
- 13** **Community Weekends**
Hear about our two recent community weekends in Sundrum and Southview
- 14** **Ian Metcalf**
The first of the interviews with one of our Trustees
- 16** **Meet Sarah**
The first interview with one of our Team
- 18** **Poem**
A poem written by Laura, a mother to a child with PWS

Meet The Team



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WELCOME



Welcome to the summer edition of the PWSA UK magazine. I am delighted to write the introduction for this edition as well as several articles. Since starting with the Association just over a year ago I have been getting to know the PWS community and I continue to seek opportunities to listen and engage with you. Please do contact me (jlodge@pwsa.co.uk) if you have any thoughts on PWSA UK and how we can better support the PWS community.

We have included news from the past few months where we have been busy with community and fundraising events. I thoroughly enjoyed attending the adult conference in Birmingham, the London Marathon, and the community weekend in Scotland. May was a very special month as the PWS awareness month. As ever the PWS community glowed orange and this year we attracted record media attention! We have included an article on transition focusing on schools which we hope you will find timely. We are always interested to hear about your experiences of different schools and accessing appropriate education.

We hope you will enjoy our new feature about the people who are PWSA UK. Interviews with Ian Metcalf and Sarah Brindle are the first of these!

Jackie Lodge



PWSA UK joined forces with FPWR UK for PWS Awareness Month.

The month focused on raising awareness of PWS and funds for our research into Ageing in PWS.

The amazing PWS community got moving – running, walking, swimming and even bum shuffling to travel around the UK. The virtual journey travelled around the whole of the UK 2,500 kilometres or 59,000 Move it May minutes. The ‘journey’ took in over 30 iconic buildings that were glowing ORANGE on 31st May. The event attracted national news coverage and social media was glowing orange with pictures of families around the country at the many different locations.

Thank you to everyone who got involved and raised over £14,000 and helped us shine a light on PWS.

RESEARCH

Clinical Trials



PWSA UK and FPWR UK are working together to support PWS research and in particular clinical trials in the UK. Trustees of the two organisations are meeting regularly to map the PWS clinical trials that are underway or in the pipeline. We are together planning a series of webinars to update the PWS community. The first session will be about the clinical trial process and the necessary steps to get effective drugs authorised and paid for use in the UK. We will then hold several further webinars where pharmaceutical companies will be invited to attend and provide updates.

We will be updating our shared website with information on current clinical trials and other related news <https://www.pwsstrongertogether.co.uk/>

The COMPASS PWS study is being done to learn more about an investigational drug in people 5-30 years old with Prader-Willi syndrome (PWS) who have hyperphagia (excessive appetite).

The investigational drug being tested in this study is called carbetocin nasal spray (or ACP-101). Carbetocin nasal spray binds to oxytocin receptors with greater sensitivity than oxytocin, a naturally occurring hormone. In the study, carbetocin nasal spray or placebo is inhaled through the nose three times each day.

This study will last approximately 19 weeks. It will involve a maximum of 5 visits to the study centre, as well as up to 2 telephone or video calls.

After the main study, participants will be invited to enrol in COMPASS PWS OLE, a long-term, open-label extension study in which all participants will receive carbetocin nasal spray for up to 36 months.

The study drug, clinic visits, and study-related procedures are provided at no cost to study participants.

There are three trial sites in the UK:

Glasgow - ingrid.macnab@ggc.scot.nhs.uk
Birmingham - faye.moore@uhb.nhs.uk

London - opening soon!
To find out more about participating in the UK trials
<https://compasspws.com/uk-en/>

TRANSITIONS

Primary to Secondary school

By Patsy Lecont, Specialist Advisor Team Manager at PWSA UK

Although the title sounds daunting, those with PWS face the same transitions as everyone else – however, it can be confusing and anxiety inducing. We find that any transition, whether it be through education, going from child to adult services or moving from home to residential or supported living settings, it really needs to be planned and thought out well.

For most youngsters, moving from primary to secondary school can be really overwhelming, and for those with PWS this can be even more so. There are a lot of things to consider and we are here to help and support you every step of the way. Remember that every child with PWS is different – some will cope really well in mainstream right the way through their education, provided the right support is in place and others may attend special school from the beginning – there is no right or wrong. You know your child best and will know whether a school setting is working for them or not. In our experience, children can struggle with a mainstream secondary setting but this by no means suggests it will be the same for your child. The following considerations are for those that are continuing in mainstream settings, and often the difficulties are not about their ability to learn.

Some of the things to consider when transitioning from primary to secondary school:

- How big is the school and how many students does it have in total?
- How does this affect the noise level and busyness of corridors?
- How many students are in each class?
- Are there vending machines in the school?
- Is the cafeteria open at lunch time or in breaktimes too?
- Will your young person cope with last minute changes, such as substitute teachers or a change of classroom for a lesson?
- What support can the school offer them to help manage all of the above?
- Will they need any differentiation in teaching methods (this is a reasonable adjustment and would be recommended by us)?



You are the expert in your son or daughter- we will always advocate for you to be heard and work together to advise on a transition plan that will help them to settle, regardless of the setting. A significant part of any transition plan should include the following:

- Giving as much notice as possible to the young person with PWS of the change from primary to secondary.
- Providing photos of the new setting and of teachers, classrooms etc.
- Allowing time for a visit - possibly in the form of sitting in on one or two lessons with support before starting
- Making sure all staff are aware of the importance of consistency and use of language - for example, all using the same words when giving instructions or direction.
- The importance of staff following the same strategies and using a positive behaviour support approach.

There are many more ways in which we can support you so any questions or for further advice, feel free to give us a call or contact supportteam@pwsa.co.uk.

Why not pass our contact details on to the new setting? We like to take a holistic approach and are happy to support any setting, whether it be mainstream or specialist.



mUPD Webinar

PWSA UK hosted a mUPD research webinar on 11th April with Professor Tony Holland, Suzannah Lester and Dr Lucie Aman.

mUPD sub type accounts for approximately 25% of all individuals with PWS. The research aims to understand what mechanisms in the brain lead to the differences we see in the subtypes. Each subtype provides a unique insight into how PWS works and allows us to better understand what having PWS means for those living with this rare and complex genetic disorder.

From the meeting we have recognised the need for a parent support group for the mUPD sub type. If you are interested in joining a group please contact supportteam@pwsa.co.uk.

Child and Adolescent Mental Health Services Specialist Prader-Willi Syndrome (PWS) Service, N&S CAMHS, Maudsley Hospital, London

Natasa Momcilovic, Specialist PWS Service Lead and Behaviour Therapist; Yailin Acosta, Assistant Psychologist; Sarah Bernard, Consultant Psychiatrist

The Specialist PWS Service sits within the Mental Health of Intellectual Disability Service and is part of the National and Specialist CAMHS. It is the only CAMHS service in the United Kingdom offering mental health and behavioural support specifically for children and young people with PWS and work closely with the Prader Willi Syndrome Association UK charity.

The Specialist PWS Service is open to young people up to the age of 18 with a diagnosis of PWS. Comorbidity of mental health disorders or severe behavioural problems is prevalent within 80% of individuals with PWS with the most common disorder being affective disorders, such as anxiety, depression and bipolar. There are four genetic differences related to Chromosome 15 which cause PWS. From a mental health perspective, we are particularly interested in Maternal Uniparental Disomy, which is associated with higher risk of developing psychosis in adolescence and adulthood and autistic symptomatology.

The Specialist PWS Service offers a multi-disciplinary team assessment to all children and young people open to our service, including intellectual disability and autism spectrum disorder assessments. Autism traits are common within the PWS phenotype and 12% - 27% of individuals with PWS receive a diagnosis of ASD.[1][2] Within our specialist service, we found a higher rate of 61% of young people referred to us have already received an ASD diagnosis or receive one through our service. Intellectual disability is also prevalent within the PWS phenotype, with most individuals with PWS having a mild to moderate intellectual disability. When working with children and young people with PWS, it's important we assess for additional diagnoses due to the high comorbidity rates, to understand the complexity of their needs and be able to recommend the most appropriate interventions to help them and their families.

Children and young people with PWS often fall through gaps in services and there is a lack of understanding of PWS due its' rare prevalence rate, which means families can be left with a lack of local support. Part of the work we do in the Specialist PWS Service is engaging with local CAMHS services and other agencies and provide consultation to professionals working with children with PWS. We also offer a number of other treatments directly to families and their network including:

- Functional behaviour assessments and positive behaviour support plans.
- Individualised PWS psychoeducation for family/carers, teachers and other relevant stakeholders.
- Advice on management of behavioural problems at home and at school.
- Consultation to local services (intervention, educational placements, transition).
- Successful initiation and monitoring of evidence based psychotropic medication as an adjunct to behavioural/psychological intervention.

The service has achieved positive outcomes for young people and families and has received positive feedback from our input. We have also received excellent feedback from families and professionals who have accessed our PWS psychoeducation. From March 2023 to March 2024, of the families and professionals who completed the feedback, 80% found the information provided 'very helpful' and 20% 'somewhat helpful'. We have also achieved outstanding outcomes from intervention, these include:

- An improvement in young people's ability to manage their behaviour.
- Families being able to resume community visits and stop isolation due to problem behaviours.
- Improvement in school's knowledge and ability to manage behaviours of young people in schools, which can also lead to higher levels of engagement at school for the young person.
- Successfully identifying appropriate schools and educational placements in partnership with the education authorities.
- Working together with educational and social services have led to successfully identifying appropriate school placements, which in turn have resulted in in significant weight loss, appropriate management of behavioural challenges, and better quality of life for young people.
- Adult services proactively planning risk assessments for food security of potential educational and respite services.

Referrals to the Specialist PWS Service are accepted from local CAMHS and paediatric services and need to remain open to these services for risk management and safety planning, whilst we jointly work with them.

[1] Lord, C., Cook, E., Leventhal, B. and Amaral, D. (2000). *Autism Spectrum Disorders*. *Neuron*, 28(2), pp.355-363.

[1] Dykens, E. M., Roof, E., Hunt-Hawkins, H., Dankner, N., Lee, E. B., Shivers, C. M., ... & Kim, S. J. (2017). *Diagnoses and characteristics of autism spectrum disorders in children with Prader-Willi syndrome*. *Journal of neurodevelopmental disorders*, 9(1), 18.

Fundraising

We have had a very busy quarter, with Awareness Month, Glow Orange and so many amazing fundraisers stepping up to the challenge and raising funds and awareness for PWS. Below are some of their amazing stories. If you have an idea for an event for would like support setting up your own, please email me, I'd love to help. kwilkinson@pwsa.co.uk.

The London Marathon

By Karen Wilkinson, Fundraising Manager
Sunday the 21st of April. We had 9 runners this year, 5 bond places and 4 ballot places. Our runners were terrific and raised over £45,000 for the association, making it our best year ever. We are so grateful to them and their donors, and a huge well done on completing this exhilarating event. We were stationed at mile 20, cheering everyone on. The PWSA UK team was made up of myself, my partner Andy, and our CEO Jackie - we were joined by Laura and Nigel from Lottoland. Some of the families of those taking part joined us through out the day too. The weather was cool for spectators but great for runners, and they did so well!!

Fiona said: "I loved running the London Marathon for PWSA UK. The marathon itself was an absolutely incredible experience, the crowds were beyond anything I imagined and there's nothing like the feeling of crossing the finish line. The support I received from Karen and the PWSA was wonderful, always there to give tips and support during training and it was lovely to see them cheering on the day too. I feel very valued as a participant and would love to fundraise for the PWSA again."



We Climbed Snowdon!

By Thea Butt, Fundraiser

We did it! We thought we might have to try again later in the year because the storm winds over the weekend made it too dangerous, but the weather gods smiled at us, and we made it up. Even the dachshund Daisy managed it under her own steam all the way. Elliot (14) and Kitty (9) were absolute troopers, even as we got nearer the summit, which was cloud-covered, and we kept thinking we'd made it, only to discover another, higher peak still to climb.

The last few metres were the most challenging part for us, but we all dug deep and got there; we are all incredibly proud of our achievement. Although we were in the clouds on the way up, just as we got to the top, the clouds lifted, and we saw some breathtaking views. We're delighted at how much money we have raised for PWSA, and we are already planning our assault on Snowdon for either later this year or next. Thank you for all your support, and we will keep in touch because we are committed to helping children like our lovely Luna in any way we can going forward.



Great Bristol Run

Julia participated in the Great Bristol Run for her friend's daughter, who has PWS. Thank you, Julia!



Didn't She Do Well

Annabelle is taking on her first big race, thinking of her best friend, who has PWS.



The Dare Skywalk

Rose, Leanne, Toby, Sarah, and Aaron took on the Dare Skywalk at the Tottenham Stadium. They even managed a stadium tour. Everyone decided to make the challenge harder by abseiling back down! Thank you; you have raised over £400.



Jacob

Jacob and his dog Peggy walked 100km in May and raised over £3,200, which is fantastic—well done, Jacob! To celebrate, Jacob and his family joined us at Battersea Power Station on the 31st of May for Glow Orange Day.



Silly-Billy Dancing

Laura transformed her home for Glow Orange Day. They held a party with friends and family and raised a whopping £1,300 - Thank you, Laura!

Elliot runs Edinburgh marathon festival with family and friends

By Sharon McCafferty, Fundraiser

This year, we had runners in all races.

It was a beautiful sunny day when Elliot Wootley (PWS), Milly Potter, Lexie Stevenson, Smirt Collins and Milly Potter all ran the 5k.

Elliot's big cousin Euan met him halfway to get to the end. We were all so proud of his achievements!

Sunday was for the half-marathon and full-marathoners. The weather was extremely wet and cold, and the half-marathoners ran all the way in the rain.

Lewis Collins, Billy Robertson and Ria McCafferty took part and all made it in good time. Billy even commented he could have ran further... marathon next time?

Myself, Oliver Wootley, Abbi, Sophie, Ella and Charlie Carter and Sharon Rastelli all ran the marathon. The rain poured at the start but eventually, the sun came out for us along the long coast road. Of course true to form it came down heavy for our last mile.

Thank you to our family and supporters on the day and to those attending events that helped us raise over £7,100 together.



Bladon House Double Marathon for Awareness Month

Bladon House School celebrated GO ORANGE Day and raised awareness of PWS. The whole school turned orange, and every student and staff member had an amazing time. We aimed to complete a double marathon challenge, one on a treadmill and one on an exercise bike. In the end, we did four marathon distances during this special day! Every student gave 100% of effort.

"Thank you to all our staff and students for making this challenge possible and also to our supporters. We managed to fundraise over £1000, including gift aid! Bladon House students and staff achieved something unique again! We did it!"



Ava

Ava has been fencing at her SEN school for the last couple of years with a British fencing project, Fencing 4 Change.

Ava is 16 and has PWS and autism, but what makes her extra special is that she has scoliosis and wears a plastic back brace full time.

She is not only a sword fighter but one of life's fighters.



Community Weekends



Sundrum, May 2024

By Karen Wilkinson, Fundraising Manager at PWSA UK

What a fantastic weekend we had. The weather was lovely, and we made great use of it by spending a day on the beach on Saturday. People paddled and picnicked, and lots took part in the Sand Castle competition, judged by our Chair of Trustees, Danny. We had joint winners.

Lots of people joined in the site entertainment. On Sunday, we had a private yoga session with Mrs Yoga, and in the afternoon, we had exclusive use of the pool and most people joined us for a swim. We were all sad to say goodbye on Monday, but we made lots of memories.



Southview, May 2024

By Sarah Brindle, PWS Specialist Advisor at PWSA UK

We all met for a fantastic Friday welcome meeting. Excitement was high as we met old and new faces and saw who we would spend our weekend with.

On day 1, we met for a morning coffee at the PWSA caravan. Conversation flowed as excitement grew for Nature Land. We soon made our way over to Nature Land for a fun-packed day, and the sunshine did not let us down. It's fair to say that Harry the Goat stole many hearts. He was also guilty of attempts to steal visitors' clothes and even someone's hair—naughty Harry!

We got back and prepared the room for the party. Our very own meet-and-greet young man welcomed the partygoers. He later doubled up as our feedback gatherer, and the feedback he gathered was truly unique, a testament to our successful event. The room was exciting, offering various crafts and activities on every table. The raffle added a continuous thrill, ensuring the energy remained high throughout the event.

Ian Metcalf

Trustee and Dad to Eve

It is with a degree of mixed emotions that I step down as a trustee from the association. I have been a trustee for almost 20 years and has been a big part of my family's PW journey.

Unbelievably Eve is now 24 years of age and when she was first born all those years ago the only real source of information was the association or the library. A very unemotional consultant simply gave us one piece of photocopied A4 paper when we first had the prognosis which was pretty bleak. After 7 weeks of what had felt like a hospital whirlwind the magnitude of the situation finally began to sink in. Trying to remain positive, we embarked on our journey where Eve would try everything to make the outcome different for her. This started at the hospital with portage and growth hormone.

I cannot remember how we stumbled across the association, but what I can remember is an extremely kind Maggie on the end of the phone and being posted out colour coded information sheets.

There was no website or social media and the only real means of communication was through the newsletter and the annual conference. My wife and I plucked up the courage to attend our first conference in Derby when Eve was about 7 months old. This gave us real opportunity to understand the syndrome and listen to stories from other awe inspiring families. Here we met and made lifelong friends.



It was after my second or third conference that I became interested in joining the trustee board and ever since I have always tried to assist the association however I knew best. I did find it slightly ironic that I was initially the company secretary as for somebody who is dyslexic this was no mean feat!

It's amazing how the association has evolved throughout the years. It offers guidance, day-to-day support, information and a sense of community throughout your whole PW journey. It really does offer so much for a relatively small charity, punching far above its weight. It now has financial stability, governance and structure in place.

During my time, I have seen so many positive changes. We now meet as a community more regularly by various means and I particularly love the family weekends. The association enables our community to communicate in so many different ways and I'm particularly proud of the Owl focus group. It is a really exciting time with so much potential and so many opportunities now for the next generation of people with PW.

I cannot end this piece without mentioning my fantastic and inspiring daughter Eve. She is an amazing young woman .

I would like to wish all trustees and all the staff the very best in all future endeavours. Good luck and I look forward to catching up at the next family weekend.

Jan Metcalf



All About Sarah

Sarah is a PWS Specialist Advisor at PWSA UK

How long have you worked for association?

I joined PWSA on April 3rd, 2023; my first meeting was a team meeting in London.

What do you get from working with the association?

I love making a difference to people and helping where I can. My motivation comes from successful wins, big or small; those little wins make us stronger and more confident. I have come from a background of working with mental health and mental capacity, and I am the lead on both for the association. I want to strengthen both of these areas.

What job/jobs have you done in the past?

When I was just a teenager, I worked with people with learning disabilities in a huge respite service near Manchester. I was introduced to the first person I had ever met with PWS. From there, I worked on a specialist behavioural unit for people with “challenging behaviours.”

From there, I moved on to working as an independent advocate in an all-male medium secure forensic unit and loved it! I eventually worked with females at a sister forensic unit. Also, I did a short time working with adolescents at a secure unit, but it wasn't for me—the adolescents were too close in age to my own children, and my mummy instinct was hard to switch off.



After this, I switched from forensics to mental capacity and again loved it. For a long while, I was the manager of a national advocacy contract that spanned the whole UK except Scotland. Still, being a single mum, the travel took its toll on my children, so I left for a position more local, just doing what I love: advocacy. Here I am today, doing what I love: advocating for PWSA UK and being a voice for our PWS community.

How many children do you have?

I have the two most adorable (I am biased) children: Abby, aged 23, and Jess, aged 22. I raised them as a single mum from the age of 2 and 3. Abby is now a qualified teacher of English language and History to secondary school children, and Jess is a nursery nurse.

What area of the country do you live in?

I live in the North West of England, near local moorlands and vast country fields. We have a local myth that if something is VERY wrong or there is “trouble brewing,” it's the Bogart lurking and casting wrongdoings. (The Bogart is a naughty, mischievous creature who likes to cause trouble. He takes the blame for lots of things that go wrong. My daughter Jess was very clumsy when she was little and would break things by accident. She always blamed it on the house Bogart.)

What do you like doing in your spare time?

I like to visit new places, go for long walks, garden, and occasionally go caving, but not as much these days as my knees complain.



Sarah's dog, Ziggy

Are there any funny stories you would like to share about yourself?

Here's a funny story about me. I have this bizarre superpower of attracting people in need. Last week, I was at Asda, just trying to get our tea, when I found myself in a car reversing situation. The owner was in a pickle, and I couldn't help but step in. I have a 'help me' beacon that only they can see!

Exciting new opportunity volunteering for PWSA UK

We are developing a new volunteer role for Outreach Volunteers to be present at PWS clinics, providing a vital link between parents/carers attending and PWSA UK. The role requires applicants to have lived experience of PWS, which may be as a parent/full-time carer of a child aged 5+, the parent of an adult with PWS, a grandparent, or a sibling.

You must commit to our volunteer training, attend monthly or quarterly clinics, work in partnership with your allocated PWS Specialist Advisor, and interact with relevant health professionals in participating clinics.

As this is a new role, we will be piloting the Outreach Volunteer Role at the following clinics: Brighton, Chelsea & Westminster, Birmingham and Stoke. If you are interested, able to attend these clinics and would like to know more about this role please contact Wendy Thomas, Volunteer Development Officer; wthomas@pwsa.co.uk.

Please note that successful applicants must provide references and undertake a DBS check. Being a volunteer means you will not be paid however, travel expenses will be reimbursed.

OTHER NEWS



Our new approach to conferences

In a post-pandemic world, we are still determining how best to provide the PWS community with information, support, and opportunities to come together. We are also examining how to reach all parts of the UK and ensure that any face-to-face meetings are as accessible as possible.

We have set ourselves a challenging agenda for 2024 with a range of events and mini-conferences. We will evaluate what works well and which approaches are more popular. Please do let us know what you think by contacting Sheila at sinwards@pwsa.co.uk.

Our face-to-face conference in Southampton on Saturday 12th October is a significant event for parents of under 16s. We will also be holding our Annual General Meeting at this event, a crucial moment for our membership to participate in shaping the future of PWSA UK. While the event will be face-to-face, we have made provisions for virtual participation to ensure everyone can be part of it.



Adult conference

We held our FIRST-ever conference for adults with PWS in April. Ruth Consterdine and Sheila Inwards organised a complete program. This included an update from Myles Kelly on his work looking at standards in residential care, a taster of the new BOSS (build our social skills) training course, as well as bingo and Zumba.

EVENTS

September

7th-15th - Ride Across Britain. Cycle from Land's End to John O'Groats.

8th - Great North Run.

20th-23rd - PWS Community Weekend at Sandford Holiday Park, Dorset.

21th - PWS Community Day at Studland Beach, Dorset.

October

12th - Face to face conference in Southampton for parents of under-16s. and the Annual General Meeting

14th - Parent to parent support group for parents of children aged 3-8, on Zoom at 8pm.

17st - Parent to parent support group for parents of children aged 8-16, on Zoom at 8.30pm.

Many more events are planned for the year, with dates to be confirmed. If you would like more information about the events above or want to hear about future events, please email admin@pwsa.co.uk

POEM

by Laura, a parent

Rehearsing the lines from books
On how to parent at our very best
Following every piece of guidance
That my midwife had to suggest.

We set sail on our journey in a small boat
Scrupulously designed with sentiment and love
As we gratefully thank god
And our lucky stars above

We have everything we need as we sail on out
There's nothing that we haven't read about
We sing and we celebrate we waited our
whole life so far
Suddenly this magical journey is everything
that we are

One mesmerising day in our beautiful journey
while the sun is beaming bright
Our little boat hit some turbulence and it gives
us quite a fright
The boat rocks to and fro and at times we
almost fall out
Not sure what's causing the boats trouble it's
something we haven't read about ,

We searched the open sea for a clue
There must be something that we can do
But on a bright sunny day without wind in the
sky
We're stumped to find a reason why

Worry and fear inevitably bubble from deep
inside
Alone in the ocean with nowhere to hide
Our reading didn't teach us what to do next,
We're still adoring our journey But we're
completely perplexed

We frantically flip through pages of our books
Terrified for our boat and about how this looks
Talks of tacks and booms and all kinds of
nautical jargon
Each challenge we read we fearfully hang on

If only we could find some experienced sailors
to show us how
To help answer the questions that we have
right now

Then like a mirage in a scene from across the
horizon
The bright orange PWSA rescue boat flies in

Like a warm embrace they sweep up our boat
with care
It's such a comfort to have an understanding
someone there
They knew everything there is to know about
our wonderful little boat
Their experience And skill keep us carefully
afloat

We scrapped the books full of jargon and fear
Now we have the right information and
guidance here
They reassure us that our journey is more
magical than ever
And that the turbulence in the beautiful
weather

It's just an anticipated part of our wonderful
ride

We embraced the turbulence and no longer
hide

And soon the water is flowing all smooth
Whilst we experience gratitude right down to
the core

We're equipped and resourceful and back on
track

But we know that should the turbulence ever
come back

We've got a family with a wealth of experience
to share

And it gives us peace to know that you are
there.

OTHER WAYS YOU CAN SUPPORT US

Did You Know We've Made Regular Donations Easier For You

You can now set up a monthly donation via our online shop. You can set the amount and manage your subscription via your online account. www.pwsa.co.uk/donations.

Become a Volunteer

There are so many ways you can volunteer, while you will need to commit some time to the association there is no minimum or maximum amount of time you need to give us. You can volunteer in person or virtually, which ever suits you. If you would like to find out more about becoming a volunteer, email Wendy at wthomas@pwsa.co.uk.

Sign Up For Easy Fundraising

Easy Fundraising is a brilliant tool. Once you have an account you can either download the app or install the extension on your internet browser. Each time you shop online you will get a pop up in the top corner offering you to add a donation into your purchase, this also happens when you shop through the app. A percentage of your purchase will automatically become a donation made to PWSA by the retailer with no extra cost to you - What's not to love?

www.easypundraising.org.uk/causes/pws/

Our Online Shop

We have lots of items available on our online shop and the best thing about using/wearing them is that you raise awareness for PWS, your purchase also counts as a donation to PWSA.



<https://pwsa-uk.ecwid.com>