



WISE OWL FEATHERS

SUMMER
2024
ISSUE
NUMBER 28

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The Newsletter for Adults
with PWS - Written by
Adults with PWS



HELLO EVERYONE

It was a really successful day, we had about 37 adults with PWS and their parents or carers. In the morning we heard from Myles Kelly who talked about the work he is doing to support residential settings. Sheila talked about a new course for adults with PWS called “Build Our Social Skills” (BOSS for short). In the afternoon we played bingo and had a Zumba session which was great fun. Have a look at the photos and see if you recognise anybody.

Welcome to your summer magazine and I hope that you are enjoying some sunny weather.

If you've been on holiday, we would love to hear about it and see some photos. If you're planning a holiday or even days out, don't forget your sun cream, it's really important.

I know that some of you came to Skegness for a weekend with PWSA UK. We had a lovely time which included a trip to the seal sanctuary. Have a look at some of the photos and some of the feedback that was collected by Adam, who is a member of our owl focus group.

There was also a community weekend in Scotland at Sundrum and they enjoyed a fun time at the beach.

We have some great stories in this magazine from Charles, Ella, Jake and Ryan. You can also read about our conference for adults with Prader-Willi syndrome which was held in Birmingham on the 20th of April 2024.

In our magazine for parents and carers, Patsy has written an article about transitions. We know that change can be difficult for you. We would love to hear from you about times when you have made changes, perhaps you have moved from one setting to another or from home to a setting or college. How did you manage the change in your normal routine?

We also have an interview with Ian Metcalf and some of you will know him as Eve's dad. He has been part of the Prader-Willi Syndrome Association for a long time and is also part of the Owl Focus Group. He talks about how important it is for PWSA UK to focus on what is important for all of our community, including

adults and children with PWS as well as their families and carers. He also says that he loves the time he gets to spend with Eve, especially at community events and that he's very proud of the young lady she has become.



MEET THE TEAM



We want to know your journey. Share it with our community!

Wise Owl Feathers is a magazine for adults with PWS, written by adults with PWS. For this to happen we need to hear from you.

If you have any stories you would like to share, any achievements, book recommendations, film recommendations, quiz ideas, we'd love to hear from you!

If you would like your story featured in the next edition of Wise Owl Feathers, please send an email or a letter in the post to our Northampton office. You must include a letter with your name, address, contact details and permission

for us to include your story in the next magazine. If you do not see what you have sent in featured in the magazine, it might be because you didn't include all your details or we received too many and could not fit your story in, but we will try our best to ensure it's included in the next issue!

We can't wait to see what you have to share with us!



PWSA UK
c/o Metcalf Commercial Decorators
3 Deer Park Road, Moulton Park,
Northampton
NN3 6RX



admin@pwsa.co.uk

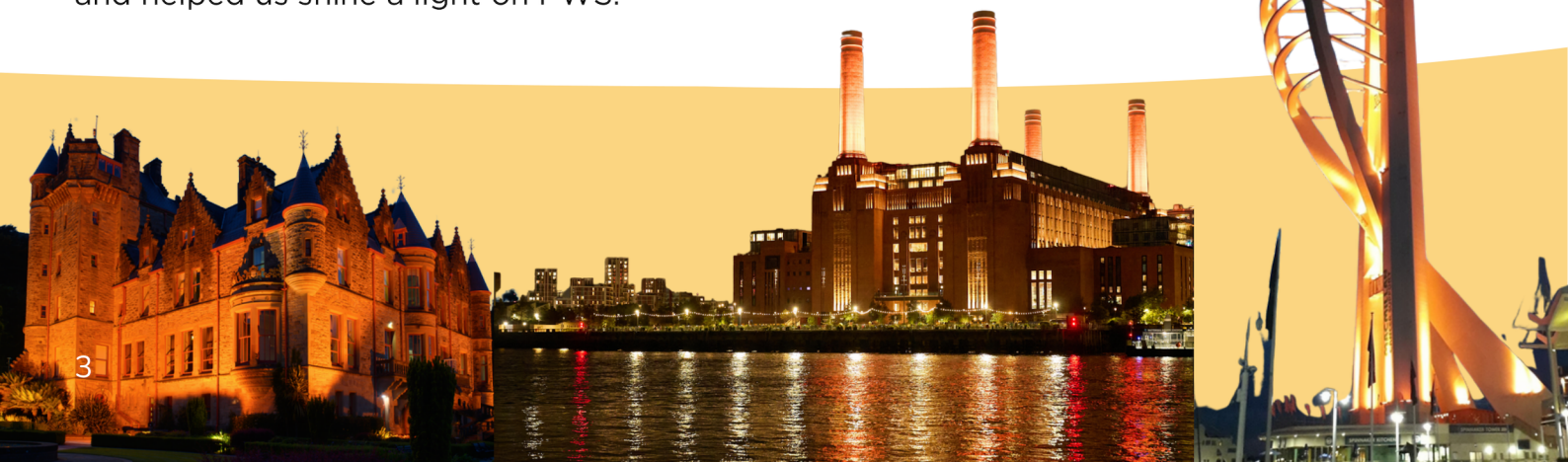
AWARENESS MONTH



PWSA UK joined forces with FPWR UK for PWS Awareness Month. The month of May 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.





*** **ADULT CONFERENCE**

We held our FIRST-ever conference for adults with PWS in April. Ruth Consterdine and Sheila Inwards organised a complete fun packed and informative programme. 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.



WHAT'S BEEN GOING ON



Wizard of Oz

Jake Heal performed in the Wizard of Oz! Read what he has said about his performance.

"I was fortunate to have the opportunity to perform in the production of Wizard of Oz after a very nervous audition. Following my audition and a very long wait, the cast list came through, and I had a part in the show! It was not the role of the Wizard or Uncle Henry, who also plays the guard in Oz, which I wanted to audition for, but I did audition for an adult ensemble, and that was the part in the show I was given. I was disappointed that I did not get a lead role. However, being in the adult ensemble was even better, as I played 4 different roles.

After the long rehearsals every Sunday and most Wednesday evenings and a hectic show week at the theatre, starting at 5pm and not finishing till 11pm all week, I was sad that it was over, but I had thoroughly enjoyed it. I played Adult Munchkin and Snow to wake the Leads up from the poppies- spell in Act 1, and in Act 2, I played an Ozian Villager and Winkies.

I loved to sing and dance on stage in all four shows. Now that I am an adult, I no longer have a 'double' to step in for me, and we even had a real dog to play Toto.

I had two solo lines in the Munchkin scene and one in the Ozian scene, which I loved. I enjoyed all of it, especially the Munchkin scene, as it was a really big number. I thoroughly enjoyed singing 'Merry Old Land of Oz,' as it was very merry.

During the final scene in Oz, I was extremely lucky to hand over the Scarecrow's Diploma in a scroll, the Lion's Medal of Courage and the Tinman's Heart Clock to the Wizard. Also, I was able to sneak up on Tinman to (pretend to) whack him over the head and chase him off the stage. 'The Winkie March' was fantastic as we marched through the edge of the audience and round the stage singing YOO-HEE-HOO! YO-HO!"



Northampton County Cricket Club

We have a brilliant relationship with Northampton County Cricket Club, and they have kindly offered us free trips to their home matches. We have been their charity of the year in the past. As Consensus is based in Northamptonshire, and we know they have residents who are cricket fans, we asked them if they would like to go. Consensus headed for a day out, had lots of fun, and enjoyed a good match.



Don't forget, if you want your pictures in the next magazine, send them in with a short write up of what activity you were doing!

ALEXANDER'S DAY OUT

Alex recently spent some time at home with his parents. During that time he walked the guide dogs for the blind trail at the Isle Of Dogs and his sisters took him to Liverpool F.C to watch the match against Crystal Palace. Alex is a Crystal Palace Season Ticket Holder. Palace won the match - You must have been their good luck charm Alex!

A LETTER FROM CHARLES

My days are hectic now as I have a lot of stuff going on throughout the week. On Mondays I work 10am - 1pm in a charity shop and then attend a disco in the evening, Tuesdays I volunteer for cafe owners to walk their dogs for an hour, Wednesdays are my 1 - 1 where I can go out for lunch and do what I want, Thursdays I go swimming one week and dog walking the other week due to members of staff, Fridays I go back into work for 10am - 1pm and then go out and buy papers on Saturdays, and every other is a takeaway, Every other Sunday I go to church.

HAYLEY IN DISNEY

Hayley sent us a picture from her visit to Disney Land - It looks like you had a great time Hayley!



MEET CHRIS

and his amazing dog Sophie

Chris is a member of our PWSA UK community. He is an adult with PWS who lives in Lothian with his dog, Sophie.

Having grown up with dogs, Chris got his dog, Sophie, a black and white Border Collie, as a tiny puppy in 2016. He wanted a Border Collie because he knew how intelligent they were from volunteering with the Dogs Trust. Along with his Personal Assistant at the time, June, who is now a firm friend of Chris, they set about training Sophie using online videos, starting with dog agility lessons in readiness for the indoor horse arena lessons with full-size agility equipment. This required moving fast, good communication with Sophie on and off the lead. It also brought great satisfaction and pride for Chris, not to mention keeping Chris and June physically challenged with all the running around!

Chris and his dog Sophie have developed a really strong bond. Sophie sleeps near Chris and keeps him in her sight. Sophie has been such a help to Chris emotionally and has enabled him to socialise within the community. Chris has gained a sense of responsibility looking after Sophie and views her as a close family member. He said, "Having Sophie is like having a daughter."

June said, "Sophie understands Chris like no one else and picks up on his changes in mood, needs and behaviours, even before they happen. She interprets everything with her acute hearing, vision and that dog super sense of smell."

With the support of June, Chris joined two charities: Pets as Therapy and Canine Concern Scotland Therapet.

These wonderful charities use volunteers with their dogs to visit all sorts of people in the community to bring cheer and affection and the therapy benefits of touching a calm, temperament-tested dog.

Chris and Sophie had no problem qualifying to visit children in schools to support their reading programmes. Chris said, "It feels good to see the children are more confident after reading to Sophie". Chris and Sophie continue to visit schools and community groups regularly, including a care home for older people, who regularly express their appreciation, helping Chris understand that he is a valuable and generous person.

Having a dog encourages physical activities such as walking and playing, which Chris has embraced up to his physical limits. Sophie is an active breed, and she also has a dog walker, surfboard, and life jacket, which are used for the times Chris swims in the wild Scottish Lochs with her!

Chris won a Volunteer of the Year award for Therapet Scotland in 2023. This was no mean feat, as only a few volunteers made the nominations out of hundreds, and each nominee had an incredible tale worthy of winning.

Recently, Chris took Sophie to the PWSA UK Sundrum holiday weekend in Ayr and enjoyed the company of many families in a relaxed setting, including the beach and the resort facilities. They joined the nature walks, yoga session and BBQ and enjoyed catching up with old friends from the PWSA UK community.





WHAT RYAN HAS BEEN UP TO

Ryan is 39 years old. He has PWS and lives in supported living.

“In April, I went to Birmingham with my mum for the PWSA UK Adults Conference. As my mum was working, I helped. On the Friday, I went to the office, met Lizzie, and helped load the car with all the things to sell in the shop.

Friday evening, I met my fiancée Charles for the first time and had dinner with him and Rowena. I had a lovely time with Charles and lots to talk about.

On Saturday, I helped set up the room, as everyone had lots to do. I sat with Charles, and we listened to Jackie, Ruth, Myles and my mum. I thought it was a very good day, and I want to go to one next year if I can. I met lots of people, made new friends, and chatted with old friends.

The next week, I interviewed for a job in a registry office.

I answered all the questions and gave many examples of things I have done. I told them I use Makaton so I can help people when they come to the registry office if they use it. The people still haven't let me know if I got the job. I have a job coach who is trying to find out for me. My job coach has helped me put my CV online so I can keep looking for work.

My flat is looking good. Mum and I did lots of painting, and this week, I am having wallpaper with owls put in my bedroom.

I haven't been well for a long time. I stopped being able to wee, and now I have to wear a bag which I don't like, but it helps me not to get more poorly. I also have high blood pressure and other things.

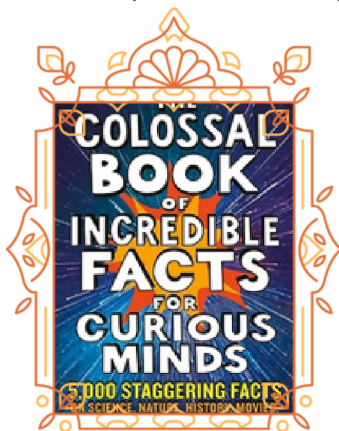
Even though I am ill, I still go to church and sea cadets, which I really like. However, I can't go swimming or to the gym at the moment because of the wee bag.

I would like to hear what everyone else does with their time.”



BOOK REVIEW

By Ruth, PWS Specialist Advisor



The Colossal Book of Incredible Facts for Curious Minds: 5,000 staggering facts on science, nature, history, movies, music, the universe and more!

By Nigel Henburst, Simon Brew, and others

Why not amaze family and friends with the reasons pandas do handstands!?

Battersea Dogs and Cats Home - A Dog a Day: 365 stories of delightful dogs to brighten every day.

By Battersea Dogs and Cats Home

Supporting the work of Battersea Dogs and Cats Home.

Beautifully packaged and illustrated throughout with charming illustrations of cheeky puppies and hounds, this is the perfect book for any lover of our four-legged friends.



READERS REVIEWS

By Jessica, Adult with PWS

A Kind of Spark

By Elle McNicoll

This book is about a girl called Addie, and she has Autism. She struggles in school and is very interested in witches.

The book also has a history of the witch trials, in which people were accused of being witches because they were different.

I think you should read this book because it is interesting to see what life is like for people who have a disability and to understand it. It's okay to be different. You are unique.

It's also a TV series, and it's perfect. It has a second series out now.



COLOURING AND WORDSEARCH

Thank you Jessica for suggesting the theme for this edition of Wise Owl Feathers



Anagram

Can you unscramble the letters below to make words related to Disney Characters?

Two words in the clue = a two-word answer.

hopiconic _____

foal _____

inrecalled _____

hetrump _____

dadnail _____

cluesher _____

amoan _____

geein _____

ininwe het hoop _____

keymic mesou _____



Wordsearch

Can you find the Disney Villains named below in the grid?

A	K	A	R	Y	R	A	T	I	G	A	N	E	R
N	R	J	M	E	L	E	F	I	C	E	N	T	L
A	A	A	S	S	M	N	H	A	D	E	S	L	A
F	N	F	K	H	H	A	N	S	M	L	N	I	A
H	D	A	C	N	E	A	Y	Z	N	D	J	V	I
E	A	R	H	D	T	R	N	L	S	M	F	E	D
S	Y	N	D	R	O	M	E	Y	K	L	O	D	C
A	O	I	N	A	A	R	S	K	U	L	O	A	L
D	E	D	R	O	E	R	C	A	A	L	E	L	A
I	E	L	E	A	C	D	A	T	L	H	C	L	Y
H	L	H	Y	Z	M	A	R	O	E	C	N	E	T
R	H	K	E	N	H	E	R	K	N	N	I	U	O
L	A	R	L	S	I	F	H	J	K	E	C	R	N
A	G	N	I	K	D	E	N	R	O	H	T	C	L

Kaa
Yzma
Hades
Shan Yu
Jafar
Hans
Syndrome
Cruella Devil
Horned King
Scar
Ratigan
Shere Kahn
Frollo
Meleficent
clayton

QUIZ

Can you get all the answers in this cartoon themed quiz correct?
Quiz created by Jessica

1) Who lives in a pineapple house under the sea?

- A. Patrick
- B. Squidward
- C. Sponge Bob Square Pants

2) What animal is Sandy in sponge Bob?

- A. Squirrel
- B. Bird
- C. Toad

3) What song is in Toy Story?

- A. You got a call from me
- B. You got a friend in me
- C. You got a new phone from me

4) What power does Pikachu have?

- A. Lightning
- B. water
- C. Fire

5) What movie has a glass slipper?

- A. Cinderella
- B. Snow White
- C. Petar pan

6) What movie has a glass slipper?

- A. Cinderella
- B. Snow White
- C. Peta pan

7) Where is this?



8) What side of scar's face has a scar?

- A. Left
- B. Right



Winner!

Congratulations to the winner of last issue's quiz, **Josh Horan** A prize is on its way to you!

Send your answers to the quiz and your completed wordsearch by 3rd September 2024 to:

PWSA UK c/o Metcalf Commercial Decorators,
3 Deer Park Road, Moulton Park,
Northampton, NN3 6RX

Name _____

Address _____

Please make sure you put the correct postage on your envelopes, including checking that your stamps have barcodes!