

# PWS NEWS



**PWS  
Updates  
and Much  
More!**

**Autumn 2024**

**Issue no. 161**



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# WELCOME

Welcome to the autumn edition of the PWSA UK magazine. Whilst it may not have been the sunniest of summers, this did not stop our amazing community days as well as our online events. Our community events included Hastings; Nene Park; and Waterways where PWS families came together for a fun filled day out.

We have news from the past few months as well as an update on forthcoming events leading into the winter. We know that events like Halloween can be a real challenge for you, so we have included some tips on how to navigate this.

We have included a feature called Mental Capacity Corner with information about some of the legal issues that families need to consider as their child with PWS moves into adulthood.

Our focus on the people who are PWSA UK continues with interviews with Dr Anne Livesey and Myles Kelly. We also report on our ongoing work with FPWR UK to engage with PWS clinical trials and keep you updated.

We hope that you are enjoying our new format newsletter, and we always welcome your feedback and comments. Please contact me [jlodge@pwsa.co.uk](mailto:jlodge@pwsa.co.uk).



*Jackie Lodge*



## Semaglutide

### and general obesity drugs

*By Robin Chung*

There is so much in the news about weight loss drugs, but we all want to know if any of these will work for people with PWS!

Some of these drugs are being tested with people with PWS to determine if these are effective and safe.

Liraglutide was negative in a PWS trial, a modified marker of weight loss. Liraglutide was safe, but there are important Gastro side effects. The most important is delayed gastric emptying, which is already slow in PWS.

Liraglutide in PWS has side effects; the advice is to NOT use GLP1RA outside clinical trials. In children only liraglutide is licenced for the treatment of severe obesity (but PWS not excluded) (BMI > 30 equivalent).

Semaglutide may work in PWS, but the drug is more potent than liraglutide ( for weight loss ) and may also have stronger side effects ( worse gastric snoring ). PWSA UK is working with researchers to secure funding for a trial which we are designing with Dr Tony Goldstone. This trial will determine if Semaglutide is effective and safe for people with PWS.

An important word of caution – you should NOT buy Semaglutide (or any other weight loss drug) for people with PWS online or through false channels. Semaglutide fake jabs may contain insulin which can be fatal. A few PWS people may qualify for it based on weight loss criteria alone but this will be prescribed by your doctor or through a tertiary weight management clinic.

There is a current shortage of Semaglutide and the inability to start new patients on Semaglutide.

More studies are needed to assess weight loss drugs for people with PWS.

## Clinical Trials

As we reported last time – we are working with FPWR UK to help promote PWS clinical trials. We held our first joint webinar on 9th July and covered the following areas:

- What are clinical trials?
- Why are they important for people with PWS and their families?
- Should you take part in one?
- Why do they take so long?

The second webinar was on 10th September and pharmaceutical companies provided updates on their PWS trials in the UK. This included:

- Aardvark (ARD-101)
- Acadia (Carbetocin)
- Harmony (Pitolisant)
- Soleno (DCCR)

Both webinars are available to view online at [www.pwsstrongertogether.co.uk/Webinars](http://www.pwsstrongertogether.co.uk/Webinars)

## Consensus

‘Prader–Willi Syndrome – guidance for Children and Transition into Adulthood’ has been accepted for publication by Endocrine Connections.

<https://bit.ly/Consensusdocument>

It was written by a ‘consensus group’ which is made up of clinicians with extensive experience in the management of PWS from the PWS specialist clinics in the UK as well as trustees of PWSA UK. A parent/carer version has been drafted (by Dr Anne Livesey) and is currently being reviewed by a group of parents and the Medical Advisory and Research Committee members. This will be available on the PWSA UK website.



# Mental Capacity Corner

*By Sarah Brindle, PWS Specialist Advisor*

Hello and welcome to the first introduction of mental health and capacity. In this first edition we will look at what having a Next of Kin (NoK) means and what we can do now to make sure our future wishes are respected if we lose our mental capacity

## **Next of Kin (NoK) – What does this mean?**

Your NoK has no specific legal rights and would not have the right to make decisions about your health and social care. Anyone can be your NoK if you say they are - they do not have to be related to you.

If someone wanted their NoK to have the right to make these decisions on their behalf, they would need to formally give these rights to them by making a lasting power of attorney (LPA).

## **To be clear on this!**

If you're married or in a civil partnership, you may have assumed that your spouse or civil partner would automatically be able to make decisions about your finances or your health and social care if there comes a time when you can no longer do so.

This is not to say their suggestions would be dismissed. A partner or close family member who knows you well will usually be asked to contribute to any plans for your care, however local authorities do not have to legally listen to them.

## **Lasting Power of Attorney (LPA) – what do I need to know as a parent?**

We can put measures in place to safeguard from this situation. We can plan now for our future and ensure that our wishes and preferences about our care are heard and respected if there is the time you need the extra support or lack capacity. This is called a Lasting Power of Attorney (LPA). There are 2 types of LPA. In this edition of capacity corner, we will look at LPA for our health and welfare.

Even thinking about this can seem daunting and we hear from lots of parents who say they did think about it doing it but kept putting it off – sometimes until its too late.

LPA's give you as a parent – or another relative, friend, or professional, the right to make decisions about a person once they are deemed not to have the mental capacity to make those decisions for themselves. You become their voice.

However, you must discuss LPA'S with your loved one **before** they lose their capacity to make decisions, as it is your son/daughter/sibling (lets call them – 'the person') who gives you the power to make decisions on their behalf. The person appoints you to be their attorney.

Once the person has been deemed not to have capacity – meaning they are unable to make decisions, it will be too late to get an LPA and may need to go to the Court of Protection for deputyship, if you feel they are making decisions that are detrimental to their health such as spending money, buying lots of unhealthy foods and putting on lots of weight.



## **What kind of Duties will the appointed LPA deputy be expected to carry out?**

A health and welfare deputy might assist in some of the following decisions:

- Daily routine, for example washing, dressing and eating
- Medical care
- Where the person

You can only make decisions when the person does not have capacity.



You must tell people involved in the person without capacity's care, when you start making decisions. This includes their:

- Friends and family
- Doctor and other healthcare staff
- Care workers, social worker and other social care staff

You may need to use/show your lasting power of attorney to prove to staff that you can act on behalf of them.

### **Money**

You might need to spend their money on things that maintain or improve their quality of life. This can include:

- New clothes or hairdressing
- Decorating their home or room in a care home
- Paying for extra support so the donor can go out more, for example to visit friends or relatives or to go on holiday

You must ask for money from whomever is in charge of the person's funds.

### **Refusing or consenting to treatment**

Some people might choose to refuse certain treatment or medical interventions and have the refusal written into their LPA.

Check the lasting power of attorney (LPA) for instructions about refusing or consenting to treatment. You'll need to:

- Show the LPA to care staff
- Sign medical consent forms
- Make decisions in the donor's best interests (BI)

You cannot always make decisions about the donor's medical treatment, for example if the donor's made a living will or has been sectioned.

### **Living wills ('advance decisions')**

This is a separate document to an LPA and is a legal statement from the person about which medical treatments they do not want. You will need to give this to care staff along with the LPA.

Hopefully the person who made the LPA for health and welfare will have also made a statement of wishes to go alongside their LPAs – a statement of wishes is basically a set of instructions to the appointee (the person they have appointed to be their voice) directing them and informing them on how to execute their role.

### **Lasting Power of Attorney (LPA) for Health and Welfare - What is it? What you need to know when applying for an LPA**

This is a legal document which anyone can make, providing we have capacity to make these choices, and are over the age of 18.

Although it must be applied for when we have capacity, the LPA for health and welfare will only come into force when we no longer have capacity.

If you become unable to make decisions for yourself in the future, someone will need to decide for you. Who will do this, will depend on the situation.

Most often professionals will make decisions about your health and social care and family or carers will decide on the smaller day to day matters.

However, you can decide when you have capacity to gift this power to someone/s you trust to make these decisions for you. This is called the LPA for Health and Welfare. You are known legally as the donor as you are "donating" the power over your liberty and the person receiving your gift is known legally as your deputy.

In Scotland they are referred to as Power of Attorney. In Northern Ireland they are referred to as Enduring Power of attorney and in England and Wales Lasting Power of Attorney. We have included the links to sign post you to each.

You can also make your LPA through a solicitor or there are various firms that also offer this service, and prices will vary depending on the solicitor's fees.



Or you can do this through the government website for your country.

The process is step by step and the form will not let you move forward until you have completed the first section correctly. If you refer to the appendix below, it will tell you what the abbreviations and acronyms mean..

<https://www.gov.uk/lasting-power-attorney-duties/health-welfare> UK and Wales

Power of Attorney - Scotland

<https://www.mygov.scot/power-of-attorney>

Enduring Power of Attorney - Northern Ireland

<https://www.nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney>

Once you have completed the form it needs to be sent to the Office of Public Guardian (OPG) who sit independently and will ensure that everyone is aware of their roles and responsibilities.

The OPG charge £82 in England and Wales, slightly more in Scotland and £151 in Northern Ireland.

You might get a reduction or exemption if you receive certain benefits so its worth checking when you come to the OPG stage.

### **To think about:**

The role of LPA for health and welfare can be a contentious one, especially if it is likely there are different opinions in what your care should look like. The person you choose must be prepared for any animosity and ensure that your past wishes and voice are heard, even if this goes against other loved one's feelings. Remember this is about YOU and what YOU would want to happen.

### **Index:**

**NoK** – Next of Kin

**LPA** – Lasting Power of Attorney

**POA** – Power of Attorney

**EPOA** – Enduring Power of Attorney

**OPG** – Office of Public Guardian

**Donor** – the person making the LPA

**Deputy** – your appointed person.

# Community Weekends

We have held two phenomenal community weekends so far this year, with the third taking place at the time this magazine is being written. There have also been a number of community days, and we are just gearing up for the Christmas parties (more details on page 15).

We want to know that the events we put on benefit you. If you have attended an event this year, please scan the QR code to complete a short survey. You can complete the survey anonymously or add your contact details to be entered into a prize draw. There are two codes: one for parents/carers and one for adults with PWS.



Feedback code for adults with PWS.  
[surveymonkey.com/r/PWSAEvent-adults-PWS](https://surveymonkey.com/r/PWSAEvent-adults-PWS)



Feedback code for parents/carers.  
[surveymonkey.com/r/PWSAEvents-parents](https://surveymonkey.com/r/PWSAEvents-parents)





# Fundraising

*By Karen Wilkinson, Fundraising Manager*

We've had an incredible few months here at PWSA UK, with so many of you taking on challenges to raise funds. Your support means the world to us and the families we help, and we're excited to share some of the highlights from recent fundraising efforts.

## Tandem Skydive for PWSA UK

A massive thank you to the 15 brave souls who took part in our tandem skydive, especially the 10-strong team from Manchester's Zuto, led by Jim. Our own Sarah also made the leap, raising over £1,000 for PWSA UK. Although Laura from Zuto admitted feeling terrified beforehand, she described the experience as surreal and peaceful, especially when the parachute opened at 15,000 feet. We are so proud of everyone who participated!

We have exciting fundraising events planned for 2025, and we need your support! From the highly anticipated "Showdown at Sunrise" on April 5, to the Great North Run, and an abseil down the Northampton Express Lift Tower, there's something for everyone. Email us at [admin@pwsa.co.uk](mailto:admin@pwsa.co.uk) to get involved!



## Chay's Fundraiser Fun Day

Chay organised a fantastic community fundraiser with over 200 people attending, complete with a football match and a bouncy castle for the kids. His efforts helped raise essential funds, and we're incredibly thankful for the continued support from everyone involved.

## Sue and Tania's Snowdon Challenge

Sue and Tania set out on a dawn walk to climb Snowdon. Although they didn't quite reach the summit, they raised over £600 for PWSA UK. Their determination and resilience were evident despite the challenging pace set by their guide, and we truly appreciate their hard work.

## Conrad's Half Marathon Success

Conrad completed his half marathon in an impressive 2:15:59—just one second off his target time! He ran in support of PWSA UK and his family, demonstrating how personal achievements can make a big difference for our cause.



# More Inspirational Fundraisers

From Brett's impressive Big Half marathon in honour of baby Luca to Betsy's clever initiative of selling her toys and raising £380, each of these acts of kindness reminds us of how special our community is. Andy's ambitious cycle from Lands End to John O'Groats and Tracey's charity night, raising £915, are further proof of the lengths people will go to support those affected by Prader-Willi Syndrome.



## Thank You!

We're endlessly grateful to everyone who has taken the time, energy, and creativity to fundraise for PWSA UK. You've all helped us make a real difference. If you're feeling inspired and have a fundraising idea of your own, we'd love to hear from you. Let's keep working together to support individuals and families living with PWS. Thank you!





# PRACTICAL PORTIONS

By Ruth Consterdine, PWS Specialist Advisor

We are really excited to be launching the Practical Portions booklet designed specifically for those with PWS. The original idea came when I received an email a few days before Christmas 2022 from Peri Wallach Therapy Assistant, working with the paediatric dietetics department at the Royal Hospital for Children in Glasgow.

Peri explained that as well as working with children who have PWS for over 9 years, she also worked in Childhood Obesity, and had previously been involved in a working group with NDR on their 'Smart Sized Portions for Children'.

Nutrition and Diet Resources (NDR) is a UK charity and you can read about their work specifically with PWSA UK on their website <https://www.ndr-uk.org/about-resources/in-development-and-review/prader-williams-syndrome>

This is a sample page of a current NDR resource and some of you may be familiar with it. However, as a parent of a child with PWS or an adult with PWS, It's really difficult to visualise what a third of these portions might look like. There is also often confusion about the different ways that people explain this:

- "A third less"
- "30% fewer calories"
- "60 - 70 % or 2/3rds of the usual amount"

Peri explained that she had come across many families, school staff, carers etc who require visual assistance regarding what an appropriate portion size should be for children with PWS, but she struggled to find any resources that would fit with the requirement for those with PWS who require 30% fewer calories than their peers.



Following initial meetings, Jenni Henderson discussed the idea with the NDR team, and they were keen to support the development of this resource and to work in partnership with PWSA UK.

Whilst the project was underway, our then new CEO Jackie Lodge took over the reins in leading the project forward.

The project was discussed with adults at our Owl Focus Group and sent out to some families for their opinions. This has been really exciting to see it develop into the 'Practical Portions for PWS' that we are about to launch.

The PWSA UK portion size resource provides practical guidance on how to regulate food intake, ensuring that individuals with PWS can lead healthier lives.

It will be a useful resource to use with health professionals, particularly dietitians, as it talks about all aspects of PWS in the introduction. It explains about the hyperphagia, or excessive appetite; the hypotonia – low muscle tone and the health risks associated with overeating. It is also full of useful hints and tips when working out how much is right for your child/adult.

# Anne Livesey

*Consultant Paediatrician and Trustee*



## **What led to your interest in PWS?**

I first met children with PWS in the late 1970s as a junior hospital paediatrician and again in the 1980s whilst working in an Endocrine clinic (hormones and growth). Since then I have seen massive changes

in information and understanding. By the late 1990s genetic diagnosis and Growth Hormone for PWS were available and Dieticians were more involved and I was a consultant specialising in child development. It became obvious that it would be better for families if the professionals saw them jointly and so we started a multi disciplinary clinic in Brighton. As this clinic grew, so did the range of our experience and knowledge of PWS. We have learnt a lot from families. We made a link with an adult Endocrinologist who is interested in PWS and so we can refer children on when they become adults.

## **How did you become aware of PWSA UK and begin to work with us?**

I became aware of the PWSA UK and its importance through parents. We were extremely fortunate in the support that the Association gave to the multi disciplinary PWS clinic over many years. We had regular attendance from the wonderfully well informed and wise Jackie Kearns and Jane Hicks through to Sheila Inwards. These colleagues extended our knowledge and the quality of what was offered by the clinic to families. Gradually I became more involved with the PWSA UK.

## **In your vast experience, what are some of the most prominent challenges faced by families? (EG – not being able to find a school placement, not meeting criteria for CAMHS/LD team)**

I learn about the day to day implications of PWS from meeting children and families.

In my experience, whilst there have been many successful stories and developments in services, PWS is not familiar to some professionals because of its relative rarity, and the variations and impact on an individual and family may initially not be understood, can be hidden and may be underestimated. There are shortages of Local Authority and Health resources generally and of well-informed specialist PWS services, although all of these do exist.

The criteria for accessing the services such as Social Care, CAMHS (Child and Adolescent Mental Health Services) and their learning disability teams may mean that children with PWS are turned away initially, e.g. because their learning levels are not severe or because 'behaviour difficulty' is not recognised as genetically based and biologically complex, etc. Local CAMHS may be both unfamiliar with PWS and unaware that they are the route for families to access national specialist PWS behaviour and mental health services at The Maudsley Hospital. There can be gaps and fragmentation in the ways services work e.g. Special Education; Disability Living Allowance systems.

All these agencies need information about what PWS means for this individual child and family. The PWSA UK provides a great deal of this information and support and the PWS health professionals can and should support the day to day facts from families. Barriers to a suitable school or service or entitlement to a payment can usually be overcome through information and evidence and sometimes require meetings of all those involved. Professionals have often said that the information about the implications of PWS for this child or young adult made a big difference and was even a revelation.



However, unfortunately when needs are highest, the provisions required, such as a suitable school, respite or residential setting, can be at their lowest and the impact on families and the requirement for advocacy about PWS greatest - and require persistence.

Suitable resources for adults are patchy and unfortunately can be another challenge.

### **And finally, what led to you wanting to become a trustee?**

I wanted to learn more about the national perspective that the Association has and from their team work and, if I could, to contribute from the frontline. There have been opportunities and I have been involved in several projects but there is a lot more to do.

## **Spook-tastic Halloween ideas!**

**Halloween is another really testing time of year for our community, so here is a handful of ideas to help you get through the night.**

Some of our family members with PWS will enjoy dressing up and handing out treats at the door, for others it will be a "Please do not knock at the door!" sign up. Remember, treats do not have to be food, they can be Halloween rubbers or pencil toppers, glow sticks, bracelets or necklaces or even spooky stickers.

It takes a little planning, but some parents and carers have found delivering non-food treats to neighbours' homes helpful before Halloween. An attached note describes PWS and requests neighbours hand out the provided treat to the child with PWS when they visit the neighbour's home for trick-or-treating.

Determine ahead of time how many houses you will visit and tell your child. Consider doing a practice walk-through a few days before Halloween.

Discuss all the possible scenarios: A large spider or skeleton in a neighbour's garden might move, the person who opens a neighbour's door might be wearing a costume, other children might be wearing scary costumes, or scary music might be playing. Talking about "scary" things ahead of time can help alleviate anxiety, making the holiday more enjoyable for everyone.

### **The Teal Pumpkin**

Participate in the Teal Pumpkin - Wouldn't it be nice if all children, even those with dietary requirements could enjoy Halloween! With the teal pumpkin they can. Teal pumpkin encourages non-food alternatives as treats. Here is the link for the teal pumpkin website <https://www.foodallergy.org/education-awareness/teal-pumpkin-project>



### **The Switch Witch**

Consider giving your sweets to the "Switch Witch" in exchange for something special. The idea is that end of the night before bedtime the children leave all their unwanted treats for the witch. Whilst they are sleeping she takes the treats away and leaves the children with something special that they want. If you want to print your own copy of the Switch Witch letter here is the link: <https://www.pinterest.co.uk/pin/848787860998001720/>

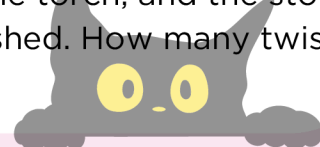
### **Spooky nightlights.**

You will need an empty plastic carton; milk bottles are good for this as they are white rather than transparent so give a spooky look. Use marker pens to decorate and put a glowstick inside. They should last a few hours at a time.



### **Storytelling Fun**

End the night with a spooky story created by your family. Turn off the lights, sit in a circle, and hand a torch to the first storyteller. They say a sentence, pass the torch, and the story continues until it's finished. How many twists will your tale take?



# Myles Kelly

*Project Manager*

## **What is your role with PWSA UK and how long have you worked for the Association?**

I am the PWSA UK's Project Manager. I was initially employed in September 2023 to explore ways that we could influence care settings to ensure people with PWS receive the best possible standards of care and quality of life. I was pleased when the role was made permanent this summer, which allowed me to focus more on the original brief and explore other ways that PWSA UK can reach out to and support the national and international PWS community; the latter included attending a conference in Berlin in May this year.

## **What do you like most about your job?**

I really like being part of a small, truly dedicated, passionate, tight-knit team that works together to improve the lives of people with PWS in our own way.

## **What job/ jobs have you done in the past?**

Since 1986, I have spent my entire career working for Gretton Homes with people with learning disabilities. That's when I first encountered PWS. Annie, Gary and Matthew all had PWS and lived with 30 others in a Grade 2 listed building in the village of Gretton, Northamptonshire. Matthew and I later became friends until he passed away in 2022. From Care Assistant to Senior Care Assistant to Care Manager to PWS Liaison Officer before being made redundant by Consensus Support Services in November 2022. After being made redundant, I dabbled with being a Partner at a local Waitrose store for approximately two weeks, which ended abruptly when I realised, not helped by wearing a disposable paper hat and apron, cutting cheese and flogging pork pies on a Waitrose deli counter, exquisite though the pork pies were, was not for me. The next day was the first day of the first Ashes test, which my partner Gail viewed as a tad suspicious. I convinced her that this was purely coincidental!

## **Tell us a little bit about your family.**

I live with my partner Gail and my 23-year-old son Harry in Little Stanion, just outside Corby. Gail also worked for Gretton Homes for 40 years. I have a stepdaughter, Bonnie, who, for the last ten years, has organised a monthly disco for people with learning disabilities, including many people with PWS from the local area. She's married to Robbie, and they are expecting their first baby in February 2025. I have two sisters and two brothers, and I'm the second youngest of the five. I have four nieces and five nephews. I see my brothers and sisters weekly for coffee, and we remain very close. I am one of five Myles' in the family!

## **Do you have any pets?**

There is another important member of the family named Rosie. She arrived at our home in February 2024 from a rescue Centre in the East Midlands.

She was first named Jumble, then, upon arrival at our home, renamed Martha before we settled on the name Rosie. However, Shadow might have been more appropriate given her daily proximity to me, often nestled into the small of my back as I try to negotiate various Teams calls. It's highly unlikely Rosie would have us wrapped around her little paw had we not lost our beloved dog Fred in the summer of 2023. Both he and Rosie were and are very important family members.

## **What do you like to do in your spare time?**

The old cliché of walking Rosie is up there, as is spending time with family and friends. I enjoy going to the cinema, watching TV, eating out, and visiting the Cotswolds and London. My favourite kind of holiday is cruising around various parts of Europe. I'm interested in politics and current affairs and still like to watch sports, mainly cricket, football, and golf. I occasionally play golf, and very often poorly!





# Good News

## Colette's Journey

In September 2023, Colette an individual with Prader-Willi syndrome (PWS), begun their transition from an Assessment and Treatment Unit Hospital to Supported Living.

Colette was in hospital for a prolonged period and struggled to lose weight. This was due to limited community access and minimal choice in her meals. When moving into her own home, Colette set herself the goal of losing weight.

From the start, Colette engaged in a range of daily activities that have become an integral part of her routine. This has been a huge contrast to when Colette was in hospital as "some days I wouldn't get out which was very annoying". Colette has returned to participating in swimming twice a week, cinema outings, bowling, coffee breaks, and is part of the local church. Colette has also been on trips out, visiting Think Tank, the Black Country Museum and the Arboretum on several occasions. These activities have positively contributed to Colette's quality of life. More recently to enjoy the warmer weather Colette bought herself a paddling pool which "is something I would never be able to do in hospital".

A pivotal part of Colette's story is her impressive weight loss. With the help of a structured meal planner tailored to her needs, and regular exercise, Colette has lost over 10kg since her move. This significant weight loss has brought her within less than one point of achieving a healthy BMI, a milestone that has improved her overall well-being.

Throughout her journey, Colette often expresses her happiness by saying, "I'm living my best life." Colette's journey demonstrates that living one's best life is not just a possibility, but a reality that can be achieved for those with PWS living in their own home. As Colette continues to develop as a person, she aims to continue losing weight and return to horse riding.



## Isobel's Award

Isobel has just won an award at the end of her first year at John Flamsteed Secondary School, Kilburn, Derbyshire. It was given to her at a recent prize-giving event by the Head of Year 7, Miss Faulding, for "Ambition". The citation that was read out before announcing that Isobel was the winner is as follows:



***"The move from primary to secondary school is huge for all students, however for some students this move is more daunting and scary for various different reasons. Right from meeting this student during extra transition I knew she would not only survive moving to secondary school, but she would thrive due to her determination, strong will power and most of all ambition to succeed in everything she puts her mind to - I couldn't be more proud of this student and her first year at JFCS. The award for ambition goes to Izzy Walker"***

Her parents are immensely proud of her and say they are grateful for the first class support she gets in school, a clear demonstration of what is possible with the right support and environment.

# Christmas Events

## North West

Party

1st December

12:00-4:00

St Paul's Hall, Wigan

## Scotland

Party

1st December

12:00-4:00

Inchyra Grange Hotel,

Falkirk

## West Midlands

Party

1st December

1:00-4:00

Bridgetown Social  
Club, Cannock

## Join the Festivities!

Christmas is coming, and we at PWSA UK are getting ready to celebrate! Our Specialist Advisors and wonderful volunteers are working hard to host fun Christmas parties and pantomimes across the UK.

Several events are already planned, and we can't wait for you to join us! To find out more or to book a place, visit our events page.

A big thank you to all our volunteers who make these celebrations possible. We hope to see you there to share in the festive joy!

**Find out more**

<https://www.pwsa.co.uk/events>

## North East

Cinderella, Panto

27th December

11:00-1:00

Consett, County  
Durham

## London

Pinocchio, Panto

4th January

12:00

The Theatre Royal,  
Stratford, London

**More TBC...**

## Cards

Our Christmas cards will soon be available to order! Priced at £5.50 for a pack of 10, they're a fantastic way to support us while raising awareness of PWS. Stock is limited, so be sure to place your order in good time to avoid disappointment.

This year, we've chosen not to offer Christmas-specific gifts, as the high costs would mean charging unfair prices. Instead, we're focusing on ensuring our funds are directed where they're most needed.

However, we have a great range of merchandise available, from teddies to beanies, so be sure to check out our collection!

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

