

**REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025
FOR
PRADER-WILLI SYNDROME ASSOCIATION UK CIO**

Johnson Tidsall Limited
Chartered Accountants
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PRADER-WILLI SYNDROME ASSOCIATION UK CIO

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PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2025

The trustees present their report with the financial statements of the charity for the year ended 31 March 2025. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

This section has been prepared in a way to ensure we meet the public benefit reporting requirements as set out in the Charity Commission reporting guidance.

- The objects of PWSA UK (the Association) are to relieve the charitable needs of people with Prader-Willi Syndrome and their families and carers by the provision of services, advice and support as the Trustees shall determine.
- The vision of PWSA UK is to overcome the challenges of Prader-Willi Syndrome.
- The mission of PWSA UK is to ensure every member of the PWS community has access to high quality care, opportunity and support, and to promote awareness, build knowledge and further research in order to overcome the challenges of PWS.
- The values of PWSA UK are to work with those affected by PWS with integrity, objectivity, accountability, openness, honesty, and clear leadership.

Prader-Willi Syndrome (PWS) is a rare complex disease which profoundly affects those with PWS and their families. PWS remains little understood relative to other conditions and as a result, the medical, social, educational, and parental support for those with PWS requires continued input and support from the Association.

The Association is UK wide and aims to meet the needs of those with PWS, parents, carers, academics, and professionals via the provision of information, training, advice, guidance, family friendly activities, crisis intervention, webinars, support for research and access to specialist expertise.

PWSA UK is a membership organisation, and the decision was taken during the year to remove all subscription fees. On 31st March 2025 we had 970 members in total which is an increase of over 20% from the previous year.

Charitable activities

The Association meets its charitable and strategic objectives by providing a range of support services for people with PWS, their families and those who work alongside them.

Our staff team continue to support the PWS community by providing a telephone helpline, email and online support, a wide range of information resources including a comprehensive website, community days and weekends. The team provides training and organises information updates through webinars and a regular newsletter. We provide peer to peer support meetings; attend PWS clinics to meet families and visit parents of newly diagnosed families at home.

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2025

ACHIEVEMENTS AND PERFORMANCE

Trustees agreed several key areas of work for the year 2024 - 25 for the six core strategic objectives of the Association. The board reviewed progress against these specific areas at the quarterly meetings.

1. To be the leading knowledge and information hub for PWS.

The website continues to be the primary information resource for the PWS community. We update information regularly and continue to ensure that this is designed for our key audiences; families, professionals and adults with PWS. The quarterly OWL magazine is printed and sent to all registered adults with PWS (currently 335). The PWS quarterly magazine is published electronically and circulated via email and is also available on the website.

An engagement and communications plan is in place which is driving a more proactive and planned approach. The 'PWS Portion Size' resource was finalised. The resource was developed through a national working group with extensive experience in PWS, working with the Nutrition and Diet Resources UK, a social enterprise charity who develop nutritional resources. The resource was peer reviewed and validated for nutritional adequacy. Common foods were used to calculate age specific food portions, and 348 photographs of these portions were taken to produce the resource. Over 2,000 copies have been ordered with over 1,400 online reads.

The 'Consensus' best practice guidance was developed by PWS clinicians and was published in Endocrine Connections. Summary information was developed for families and is available on the PWSA UK website under 'Are you getting the Right Care? PWS Best Practice Guidelines'.

PWSA UK delivered 37 training sessions during the year with 845 participants. These training sessions were mainly for professionals working in education, health and social care. This is an increase of over 50% from the previous year. The BOSS (Build our Social Skills) training for adults has been piloted and is being delivered during 2025. Makaton is a useful communication tool and level 1 training has been delivered for 11 parents. Trustees have agreed to prioritise training to support standards of care and support for people with PWS.

2. To provide the best possible support to the PWS community.

The PWSA UK team supported families and professionals throughout the year with 1,160 people accessing our services which resulted in 2,755 actions (phone calls, letters, and meetings) to resolve the issues.

Our prime sources of requests for help were:

- Helpline 25%
- Email 60%
- Facebook: 6%
- Clinics/ Family Net: 1%
- Website: 8%

More families are contacting us via email with a modest reduction in the number of calls to the helpline. An online conference was held in September 2024 with over 100 people joining the meeting.

19 community events were held across the UK with 624 attendees. Community days and weekends are a vital opportunity for PWS families to meet and connect and to reduce the isolation of living with a rare condition. Two new parent-to-parent forums were established in response to requests from members. The first is for mUPD parents and the second is specifically for families with adults aged over 40 years.

PWSA UK is committed to working with PWS residential care providers to improve standards of care and quality of life for adults with PWS. A forum of PWS providers has been established with opportunities to learn and network through online webinars and meetings. A Charter for Care Homes has been drafted and will be rolled out to encourage adoption of core standards. A provider list (PWS Care Home directory) is being developed and will include expanded information for parents and commissioners.

A survey of parents of adults in care home settings has been undertaken as well as planning for regular 'listening' meetings. PWSA UK has worked in an advisory capacity with several providers who are looking to set up new services in underserved parts of UK.

3. To be the voice of those affected by PWS.

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2025

The Association monitors the issues and challenges faced by the PWS community and reviews its information and support to reflect these needs. 495 responses to monitoring and evaluation surveys have been received during the year. Information from the surveys is analysed with reporting to the staff and board of trustees to help inform plans and make changes and improvements to services.

Membership of PWSA UK grew from 800 to 971 members which is an increase of 171 or over 20%. The Association is committed to engaging with and listening to its members and holds biannual Town Hall events. Working with and supporting adults with PWS remains a key priority across the Association and the OWL (Our Way of Life) group made up of adults with PWS has been promoted and expanded with direct reporting to the board of trustees.

The Association remains committed to working in partnership with allied PWS organisations FPWR UK and IPWSO as well as organisations with overlapping objectives such as Sibs UK, The Genetic Alliance and the Disabled Children's Partnership to achieve more by working together. There has been a concerted effort to develop effective working relationships during the year. Partnerships have been developed with Smith-Magenis Syndrome Foundation UK, Angelman UK and the Disabled Children's Partnership where there have been shared areas of interest and opportunity to achieve more by working together.

4. To develop and maintain regional reach.

PWSA UK is committed to supporting all people impacted by PWS and annually map our reach and engagement. There has been a 20% increase in the numbers of people engaging with PWSA UK across the UK and notably higher in Scotland and London.

Funding was secured to employ a part time PWS Specialist Support Worker in Northern Ireland. Work has started to reach PWS families in Northern Ireland and engaging with health, education and social care professionals.

We remain committed to increasing our in-country support for Scottish PWS families and this is a priority for 2025. Over the past year we have seen an increase of 2.3% of non-white members. We can now track our year-on-year progress of reaching isolated families against the baseline established in 2024.

The number of volunteers working with PWSA UK has grown through the year from 31 to 37 an increase of almost 20%. In addition, the Association is fortunate to benefit from the voluntary support of the Board of Trustees as well as the OWL focus group made up of adults with PWS. Outreach at PWS clinics has been increased through the recruitment of 2 new volunteers during the year. A priority is to increase outreach through recruitment of additional volunteers as well as allocating staff time to this important objective of reaching families impacted by PWS.

5. To support and promote research into the management and alleviation of the challenges of life with PWS.

PWSA UK continues to work in partnership with FPWR UK through the PWS Stronger Together initiative. Through this collaboration three webinars have been delivered to provide updates on PWS clinical trials.

PWSA UK continues to provide input into trials and studies as the patient voice as well as promoting opportunities for participation in clinical trials and research.

During May 2024 PWS Stronger Together ran a campaign to raise awareness of PWS and raise funds for research into ageing in PWS. £14,000 was raised and buildings across the UK were lit up in orange on PWS awareness day.

The Medical Advisory and Research Committee reviewed and recommended proposals to fund a survey into premature deaths of people with PWS. The principal aim of the study is to help prevent future early deaths of people with PWS. Research proposals have been submitted for ethics approval.

6. To sustain the charity.

Three new trustees were appointed during the year bringing with them skills in fundraising, communications and marketing. Trustees identified a gap in trustees' experience of parenting an adult with PWS. The board continues to actively manage succession planning and recruit trustees to meet any gaps in skills, knowledge and experience.

The first Impact Report was produced and published. Monitoring and evaluation have been embedded into the work of the Association to feed into a culture of learning and responding to feedback. All organisations are at risk of cyber-attacks and staff have undertaken cyber security awareness training and are subject to periodic testing.

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2025

Income from Trusts and Foundations has seen a drop from £100K to £40K. This is consistent with the charity sector experience of increased competition and reduced availability of funds. This has been offset by increased income from legacies, major donors and events. A new fundraising plan has been agreed which focuses on diversification and developing digital skills and the supporter journey.

Trustees continue to closely monitor staffing costs whilst recognising that the work of the Association is delivered by the staff team.

Job descriptions and person specifications for all staff have been reviewed, updated and agreed. New HR contracts have been issued and signed. Management of Payroll, pensions, HMRC and HR policies have been transferred to a new HR system to ensure compliance and improve efficiencies.

Volunteering

The Association has always relied upon the commitment, goodwill, knowledge, and experience of its volunteers. We currently have 37 registered volunteers who organise and support community events and facilitate parent to parent meetings online. Trustees and the OWL group volunteer their time, knowledge, skills and lived experience to guide the Association. The Association also relies on the goodwill and support of informal volunteers who raise funds, marshal at events, provide specialist skills to the charity, and much more.

We will always be grateful to our community and volunteers - without whom the charity simply would not be able to achieve what it does year on year.

Income Generation

PWSA UK is not only member-led but also depends on the fundraising efforts of its members for much of its funding. Without this, the Association would be unable to operate and continue to provide its vital services to the PWS community. The fundraising environment remains challenging with the ongoing cost of living crisis and increased competition for Trusts and Foundations funding.

We are hugely grateful to the following:

- Awards for All (Children in need) - NI - £18,073
- Better Breaks Scotland - £6,750
- Toyota - Wales - £1,824
- Hanley Trust - £1,000
- J4G Grant - Core - £750
- Inch Cape Foundation - Scotland - £750
- Augustine Courtauld - core - £2,000
- Harry Krish Mootoosamy Foundation - Music Therapy at events/weekends - £2,000
- Philip Barnes & Co - Research - £1,500
- Saturday Hospital Fund - new diagnosis packs - £1,925
- St James Place - core - £2,500
- Ecclesiastical Group - core - £1,500
- Souter Charitable Trust - walkovers - £1,000
- Happy Days Charity - Comm weekend - £688

FINANCIAL REVIEW

Financial position

In the financial year under review, the Association received income of £ 657,800 (2024: £497,574) and incurred expenditure of £507,975 (2024: £501,101) resulting in a surplus on operating activities of £149,825 (2024; deficit £3,527).

Income increased by 32 % whilst expenditure increased by 1 % compared with 2023-4.

Total funds as at 31 March 2025 stood at £ 580,098 (2024: £430,273) of which £46,723 (2024: £63,618) are restricted funds.

Of the remaining funds £144,700 (2024: £116,003) are designated for specific projects.

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2025

FINANCIAL REVIEW

Principal funding sources

The principal activities of the Association have been funded from our core income. The Association remains reliant upon the efforts of our membership and others associated with the charity for their fundraising efforts.

The general environment for small charities continues to be financially challenging and the Association's ability to maintain a position of mid-term viability remains key to maintaining our charitable services. Competition for and availability of funding from Trusts and Foundations is a challenge across the charitable sector and it is vital that PWSA UK continues to diversify its income.

Long term financial sustainability remains a top priority, and the Association continues to seek to diversify income sources.

Investment policy and objectives

The investment policy of the Association is determined by the Trustee Board and enacted by the Chief Executive. As of 31st March 2025, all reserves were held in the bank deposit account and money market short term deposits. There are no investments in equities, gifts, or bonds.

Reserves policy

It is the policy of the Association to maintain a general reserve as well as a designated reserve to support specific future projects. The "designated" reserves at the end of the financial year were £144,700. The charity Trustees will review this during the coming financial year to realign with a review of the plans, budgetary constraints and assessment of priorities.

The Trustees have agreed that the unrestricted reserves should not fall below six months' operating costs. The balance of the Association's general reserves at the 31st of March 2025 is £388,676 which represents 9 months of unrestricted operating costs which is in line with the target set by Trustees.

Pension Commitments

The Association operates a defined contribution pension scheme for its staff. PWSA UK reached their staging date for automatic enrolment in March 2016 and as required all eligible staff are enrolled into a qualifying pension scheme.

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2025

FUTURE PLANS

Strategic Objectives for 2025-26

Trustees continue to work towards the core strategic objectives of the Association. For each of these several key areas of work have been agreed for the year 2025-26

1. To be the leading knowledge and information hub for PWS.

- Continue to improve the website, with a focus on SEO and planning a future review of the suitability of the website
- Develop and maintain clear, multi-use resources on behaviour, mental health, legal and transition information, ageing, PWS related terminology, and care options for adults with PWS, with scheduled reviews and a content sign-off process.
- Conduct a full review of training needs and plan annual webinars, deliver and evaluate BOSS training, appoint a training manager, and develop accredited training for professional caregivers.

2. To provide the best possible support to the PWS community.

- Deliver engaging community events and peer support groups, while using face-to-face opportunities to connect, share, and support informal learning within the PWSA UK community.
- Provide effective one-to-one support for individuals with PWS and their families, supported by expert panel review, improved data systems, and a collective advocacy approach for parents of care home residents.
- Grow a community of professional caregivers, build networks with expert social workers, promote PWS awareness at key conferences, and support the development of specialist services by identifying gaps and needs.

3. To be the voice of those affected by PWS.

- Establish a system to track trends and inform support and campaigns.
- Strengthen the OWL group's volunteer role.
- Develop and implement a working care plan for adults with PWS.
- Promote and grow free membership beyond 1,000.
- Strengthen engagement through surveys, listening events, and targeted campaigns.
- Developing evidence-based policy on key issues and building strategic partnerships to amplify the voice of those affected by PWS.

4. To develop and maintain regional reach.

- Conduct annual mapping to assess reach and service provision across UK.
- Grow clinic outreach and networks (including isolated and diverse communities).
- Secure funding for a specialist role in Scotland.
- Expand and centralise volunteer management.
- Explore the development of a hub-and-spoke model to boost engagement with key services and professionals.

5. To support and promote research into the management and alleviation of the challenges of life with PWS.

- Support and promote research partnerships and clinical trial engagement in partnership with FPWR UK through PWS Stronger Together.
- Align PWSA UK priorities with evidence-based studies.
- Continue to provide regular research updates.
- Conduct a survey into PWS-related deaths.

6. To sustain the charity.

- Maintain strong governance with succession planning, appoint a new Chair by 2026 and plan a full strategic review for 2026-27.
- Embed monitoring and evaluation using impact data
- Upgrade IT and cybersecurity and develop business continuity plans.
- Review CRM for better integration and fundraising.
- Urgently diversify income amid growing competition for trusts and foundations, exploring digital fundraising campaigns, developing the supporter journey, and increasing income from corporates, pharmaceuticals, and training.
- Ongoing prudent financial management to match expenditure to income, as well as ongoing control of fixed costs.
- Increase support and development of volunteers.
- Foster a learning culture with continuous improvement and refresh and embed charity values.
- Develop monitoring of training, compliance, and asset management through HR system.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, the charity constitution.

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2025

STRUCTURE, GOVERNANCE AND MANAGEMENT

Charity constitution

The Prader-Willi Syndrome Association UK (the Association) was originally registered as a charity on 13 May 1982: Charity Number 284583. In 2014 a new Charitable Incorporated Organisation (CIO) was formed and registered with the Charity Commissioners under Charity Number 1155846. The original Unincorporated Organisation Charity Number 284583 was then merged into the new CIO and all assets and liabilities transferred. The original unincorporated organisation was then closed and removed from the Charity Commissioner's register.

PWSA UK was registered in October 2024 with the Scottish Charity Regulator (OSCR) with the new number SC053700.

The CIO PWSA UK is controlled by its governing document, and its registered address is in Northampton in UK.

Organisational structure

The Association is governed by a Board of Trustees consisting of not less than four members of the Association. These are elected by the membership for three years at the Annual General Meeting (AGM). At the first meeting after the AGM, the Trustees elect from its number a Chairman and Treasurer who are known as the Honorary Officers of the Association. The Board of Trustees normally meets four times a year with one face to face meeting in London.

A new recruitment process has been agreed by the Trustees to ensure that Trustees are selected based on required skills and experience. As part of the ongoing review of governance the previous working groups were closed and replaced by new sub-committees which better meet the needs of our operations:

- Finance and General Purposes Committee
- Medical Advisory and Research Committee
- Services, Information and Training Committee
- Fundraising and Communications Committee

The committees operate within agreed Terms of Reference and make recommendations to the Trustee Board.

The day-to-day management of the Association's activities are delegated to the Chief Executive who reports on progress against plans agreed by the board. The Association has a supervisory and appraisal system in place. All employees have a designated line manager who directs and supports staff to fulfil their own and the organisation's objectives which are consistent with the strategic aims set by the Trustee Board.

Declaration of Interest and Internal Controls

The Association has in place general decision-making and financial controls; the Chief Executive and all staff members are fully accountable to the Trustee Board and there are set levels of financial delegation requiring Trustee approval.

The Association has agreed a Declaration of Interest statement that requires board meeting participants to declare any pecuniary and non-pecuniary interest at the outset of every Board meeting. This is in addition to the Register of Interests and transactions with related parties' annual declaration.

Risk management

The Trustee Board have agreed a risk management policy covering the principal areas of Governance, Operational, Financial, Environmental and External, Law and Regulation.

Trustees have developed a risk management register which identifies and assesses the likelihood and impact of organisational risks. Actions are agreed to mitigate risks to help Trustees identify and focus on residual risks.

The risk management policy and register are reviewed annually by the board. The board reviews higher risks on a more frequent basis to help manage uncertainty and to ensure delivery of objectives and the long-term survival of the Association.

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2025

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number

England and Wales: 1155846 Scotland: SC053700

Principal address

C/O Metcalf Commercial Decorators Ltd
Unit 5, 3 Deer Park Road
Moulton Park Industrial Estate
Northampton
NN3 6RX

Royal Patron

HRH The Princess Michael of Kent

Patron

Prof Tony Holland CBE

Trustees

Lt Col Danny Leslie MBE (Chairman)
Matthew Christensen (Treasurer)
Andrew Abbott
Catherine Carey (resigned 15 September 2024)
Dr Robin Chung
Dr Evelien Gevers
Anne Good
Dr Anne Livesey
Ian Metcalf (stood down 19 October 2024 - end of maximum term of office)
Rebecca Neish (appointed 19 October 2024)
Susan Passmore
Laura Pearson (appointed 19 October 2024)
Rose Polaschek
Karen Potts
Stephanie Sokolowski (resigned 19 July 2024)
Fiona Swinhoe (appointed 19 October 2024)

**Chief Executive and
Honorary Secretary**

Jackie Lodge

Independent Examiner

Johnson Tidsall Limited
Chartered Accountants
81 Burton Road
Derby
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DE1 1TJ

Bankers

HSBC Bank Plc
1 St Peters Street
Derby
Derbyshire
DE1 2AE

Approved by order of the board of trustees on18/10/25..... and signed on its behalf by:



.....
D Leslie - Trustee

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF PRADER-WILLI SYNDROME ASSOCIATION UK CIO

Independent examiner's report to the trustees of Prader-Willi Syndrome Association UK CIO

I report to the charity trustees on my examination of the accounts of Prader-Willi Syndrome Association UK CIO (the Trust) for the year ended 31 March 2025.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under Section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under Section 145(5)(b) of the Act.

Independent examiner's statement

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales, which is one of the listed bodies.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by Section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



David Mellor

Johnson Tidsall Limited
Chartered Accountants
81 Burton Road
Derby
Derbyshire
DE1 1TJ

Date:

29/10/2025

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 MARCH 2025

	Notes	Unrestricted funds £	Restricted funds £	2025 Total funds £	2024 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	3	488,353	44,985	533,338	402,450
Charitable activities	6				
Charitable activities		102,206	-	102,206	79,177
Other trading activities	4	5,519	-	5,519	4,531
Investment income	5	16,737	-	16,737	11,416
Total		<u>612,815</u>	<u>44,985</u>	<u>657,800</u>	<u>497,574</u>
 EXPENDITURE ON					
Raising funds	7	16,761	408	17,169	13,798
Charitable activities	8				
Charitable activities		469,216	21,590	490,806	487,303
Total		<u>485,977</u>	<u>21,998</u>	<u>507,975</u>	<u>501,101</u>
 NET INCOME/(EXPENDITURE)					
Transfers between funds	18	126,838 39,882	22,987 (39,882)	149,825 -	(3,527) -
Net movement in funds		166,720	(16,895)	149,825	(3,527)
 RECONCILIATION OF FUNDS					
Total funds brought forward		366,655	63,618	430,273	433,800
 TOTAL FUNDS CARRIED FORWARD		<u>533,375</u>	<u>46,723</u>	<u>580,098</u>	<u>430,273</u>

The notes form part of these financial statements

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

BALANCE SHEET 31 MARCH 2025

	Notes	Unrestricted funds £	Restricted funds £	2025 Total funds £	2024 Total funds £
FIXED ASSETS					
Tangible assets	14	3,744	-	3,744	3,598
CURRENT ASSETS					
Stocks	15	3,051	-	3,051	4,186
Debtors	16	20,398	-	20,398	9,853
Cash at bank and in hand		<u>513,515</u>	<u>46,722</u>	<u>560,237</u>	<u>421,658</u>
		536,964	46,722	583,686	435,697
CREDITORS					
Amounts falling due within one year	17	(7,332)	-	(7,332)	(9,022)
NET CURRENT ASSETS		<u>529,632</u>	<u>46,722</u>	<u>576,354</u>	<u>426,675</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>533,376</u>	<u>46,722</u>	<u>580,098</u>	<u>430,273</u>
NET ASSETS		<u>533,376</u>	<u>46,722</u>	<u>580,098</u>	<u>430,273</u>
FUNDS	18				
Unrestricted funds				533,376	366,655
Restricted funds				<u>46,722</u>	<u>63,618</u>
TOTAL FUNDS				<u>580,098</u>	<u>430,273</u>

The financial statements were approved by the Board of Trustees and authorised for issue on18/10/25..... and were signed on its behalf by:



D Leslie - Trustee



K Potts - Trustee

The notes form part of these financial statements

PRADER-WILLI SYNDROME ASSOCIATION UK CIO**CASH FLOW STATEMENT
FOR THE YEAR ENDED 31 MARCH 2025**

	Notes	2025 £	2024 £
Cash flows from operating activities			
Cash generated from operations	1	<u>124,402</u>	<u>(32,134)</u>
Net cash provided by/(used in) operating activities		<u>124,402</u>	<u>(32,134)</u>
 Cash flows from investing activities			
Purchase of tangible fixed assets		(2,560)	(3,260)
Interest received		<u>16,737</u>	<u>11,416</u>
Net cash provided by investing activities		<u>14,177</u>	<u>8,156</u>
 Change in cash and cash equivalents in the reporting period		<u>138,579</u>	<u>(23,978)</u>
Cash and cash equivalents at the beginning of the reporting period		<u>421,658</u>	<u>445,636</u>
 Cash and cash equivalents at the end of the reporting period		<u>560,237</u>	<u>421,658</u>

The notes form part of these financial statements

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE CASH FLOW STATEMENT FOR THE YEAR ENDED 31 MARCH 2025

1. RECONCILIATION OF NET INCOME/(EXPENDITURE) TO NET CASH FLOW FROM OPERATING ACTIVITIES

	2025 £	2024 £
Net income/(expenditure) for the reporting period (as per the Statement of Financial Activities)	149,825	(3,527)
Adjustments for:		
Depreciation charges	2,103	2,536
Loss on disposal of fixed assets	311	-
Interest received	(16,737)	(11,416)
Decrease/(increase) in stocks	1,135	(997)
Increase in debtors	(10,545)	(5,090)
Decrease in creditors	(1,690)	(13,640)
Net cash provided by/(used in) operations	<u>124,402</u>	<u>(32,134)</u>

2. ANALYSIS OF CHANGES IN NET FUNDS

	At 1/4/24 £	Cash flow £	At 31/3/25 £
Net cash			
Cash at bank and in hand	<u>421,658</u>	<u>138,579</u>	<u>560,237</u>
	<u>421,658</u>	<u>138,579</u>	<u>560,237</u>
Total	<u>421,658</u>	<u>138,579</u>	<u>560,237</u>

The notes form part of these financial statements

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025

1. STATUTORY INFORMATION

Prader-Willi Syndrome Association UK CIO is a charity, registered in England and Wales. The charity's registered charity number and business address can be found in the reference and administrative details of the Report of the Trustees.

2. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

The currency basis for the preparation of these financial statements is pound sterling (£).

Going concern

The trustees regularly monitor the charity's reserves policy, risk assessment and cash flow to assess the viability of the charity. To date, no material uncertainties exist that would affect the preparation of the financial statements on a going concern basis.

Significant judgements and estimates

The following judgements (apart from those involving estimates) have been made in the process of applying the charity's accounting policies that have had the most significant effect on amounts recognised in the financial statements:

Legacies - when calculating amounts due on legacies, management considers the wills of the deceased, executors accounts, notifications received from executors and consultation with solicitors.

Grants - when calculating grant commitments, management considers the nature of the grants as being within the charity's objectives, their entitlement and the possible future benefits for people affected by PWS.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Donated services and goods are recognised as income when the charity has control over them, the economic benefit is probable and can be measured reliably. In accordance with the Charities SORP (FRS102), volunteer time is not recognised. Information about their contribution is provided in the Trustees' Annual Report.

For donations to be recognised the charity will have been notified of the amounts and the settlement date. If there are conditions attached to the donation and this requires a level of performance before entitlement can be obtained, then income is deferred until those conditions are fully met or the fulfilment of those conditions is within the control of the charity and it is probable that they will be fulfilled.

For legacies, entitlement is the earlier of the charity being notified of an impending distribution or the legacy being received. At this point income is recognised.

Income from trading activities includes income earned from fundraising events and trading activities to raise funds for the charity. Income is received in exchange for supplying goods and services in order to raise funds and is recognised when entitlement has occurred.

Investment income is earned through holding assets for investment purposes such as shares and bank deposit accounts. It includes bank interest. It is included when the amount can be measured reliably.

Debtors

Other debtors are recognised at the settlement amount due. Prepayments are valued at the amount prepaid.

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

2. ACCOUNTING POLICIES - continued

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

Creditors

Creditors are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors are recognised at their settlement amount.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Fixtures and fittings - 25% on cost

Tangible fixed assets are stated at cost or deemed costs less accumulated depreciation. Cost includes costs directly attributable to making the asset capable of operating as intended.

Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

Stock is valued on a first in first out basis (FIFO).

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

The charity has both restricted and unrestricted funds. All funds are used to benefit and promote its charitable objects.

Restricted funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose and the restriction means that the funds can only be used for specific projects or activities.

When donors specify that donations and grants are for particular purposes which do not amount to pre-conditions regarding entitlement, this income is included in incoming resources of restricted funds when receivable. The relevant expenditure is then matched as restricted expenditure.

Unrestricted funds are general funds that are available for use at the trustees' discretion in furtherance of any objectives of the charity.

Designated funds are unrestricted funds set aside at the discretion of the trustees for specific purposes.

Pension costs and other post-retirement benefits

The charity operates a defined contribution pension scheme. Contributions payable to the charity's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

Operating leases

Rentals applicable to operating leases where substantially all of the benefits and risks of ownership remain with the lessor are charged to the SOFA on a straight line basis over the period of the lease.

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

2. ACCOUNTING POLICIES - continued

Operating leases

Reserves

The charitable company maintains a level of reserves required to fulfil its objectives. The trustees monitor reserves at regular meetings.

Financial instruments

Financial instruments are classified and accounted for, according to the substance of the contractual arrangement, as either financial assets, financial liabilities or equity instruments. An equity instrument is any contract that evidences a residual interest in the assets of the company after deducting all of its liabilities.

3. DONATIONS AND LEGACIES

	2025	2024
	£	£
Donations	349,236	402,450
Legacies	<u>184,102</u>	<u>-</u>
	<u>533,338</u>	<u>402,450</u>

4. OTHER TRADING ACTIVITIES

	2025	2024
	£	£
Promotional sales	<u>5,519</u>	<u>4,531</u>

5. INVESTMENT INCOME

	2025	2024
	£	£
Deposit account interest	<u>16,737</u>	<u>11,416</u>

6. INCOME FROM CHARITABLE ACTIVITIES

	Activity	2025	2024
		£	£
Conferences holidays & support	Charitable activities	23,397	20,965
Fundraising events	Charitable activities	<u>78,809</u>	<u>58,212</u>
		<u>102,206</u>	<u>79,177</u>

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

7. RAISING FUNDS

Other trading activities

	2025	2024
	£	£
Fundraising expenditure	<u>17,169</u>	<u>13,798</u>

8. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 9) £	Support costs (see note 10) £	Totals £
Charitable activities	<u>483,676</u>	<u>7,130</u>	<u>490,806</u>

9. DIRECT COSTS OF CHARITABLE ACTIVITIES

	2025	2024
	£	£
Staff costs	393,807	406,353
Insurance	1,631	1,316
Telephone	4,950	4,670
Postage and stationery	4,035	6,451
Printing costs	1,114	5,012
Bank charges	316	419
Events	14,918	10,755
Travel and accommodation	9,420	8,158
Staff training	3,192	3,150
IT costs	17,906	16,495
Office machine maintenance	77	4,757
Subscriptions	4,640	2,738
Projects support	18,956	3,061
Research	8,714	5,875
	<u>483,676</u>	<u>479,210</u>

10. SUPPORT COSTS

	Management £	Human resources £	Other £	Governance costs £	Totals £
Charitable activities	<u>501</u>	<u>46</u>	<u>2,414</u>	<u>4,169</u>	<u>7,130</u>

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

10. SUPPORT COSTS - continued

Accountancy and legal fees include £3,500 in respect of the Independent Examination fee.

Support costs, included in the above, are as follows:

	2025 Charitable activities £	2024 Total activities £
Trustees' expenses	501	1,197
Sundries	46	254
Depreciation of tangible fixed assets	2,103	2,536
Loss on sale of tangible fixed assets	311	-
Accountancy and legal fees	<u>4,169</u>	<u>4,106</u>
	<u>7,130</u>	<u>8,093</u>

11. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2025 nor for the year ended 31 March 2024.

Trustees' expenses

	2025 £	2024 £
Trustees' expenses	<u>501</u>	<u>1,197</u>

Trustees' expenses relate to attendance at meeting costs.

12. STAFF COSTS

	2025 £	2024 £
Wages and salaries	348,426	359,892
Social security costs	28,329	30,499
Other pension costs	<u>17,052</u>	<u>15,962</u>
	<u>393,807</u>	<u>406,353</u>

The average monthly number of employees during the year was as follows:

	2025	2024
Charitable activities	11	9
Management and administration	<u>1</u>	<u>1</u>
	<u>12</u>	<u>10</u>

During the year one employee (2024 one employee) received total employee benefits of more than £60,000.

The key management personnel of the charity comprises the Chief Executive Officer. The total employee benefits of the key management personnel of the charity, including employer's pension contributions, amounted to £88,157 (2024: £89,173).

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

13. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	324,108	78,342	402,450
Charitable activities			
Charitable activities	79,177	-	79,177
Other trading activities	4,531	-	4,531
Investment income	11,416	-	11,416
Total	<u>419,232</u>	<u>78,342</u>	<u>497,574</u>
EXPENDITURE ON			
Raising funds	12,083	1,715	13,798
Charitable activities			
Charitable activities	<u>437,468</u>	<u>49,835</u>	<u>487,303</u>
Total	<u>449,551</u>	<u>51,550</u>	<u>501,101</u>
NET INCOME/(EXPENDITURE)	(30,319)	26,792	(3,527)
Transfers between funds	<u>(5,242)</u>	<u>5,242</u>	<u>-</u>
Net movement in funds	(35,561)	32,034	(3,527)
RECONCILIATION OF FUNDS			
Total funds brought forward	402,215	31,585	433,800
TOTAL FUNDS CARRIED FORWARD	<u>366,654</u>	<u>63,619</u>	<u>430,273</u>

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

14. TANGIBLE FIXED ASSETS

	Fixtures and fittings £
COST	
At 1 April 2024	25,889
Additions	2,560
Disposals	(623)
At 31 March 2025	<u>27,826</u>
DEPRECIATION	
At 1 April 2024	22,291
Charge for year	2,103
Eliminated on disposal	(312)
At 31 March 2025	<u>24,082</u>
NET BOOK VALUE	
At 31 March 2025	<u>3,744</u>
At 31 March 2024	<u>3,598</u>

15. STOCKS

	2025 £	2024 £
Finished goods	<u>3,051</u>	<u>4,186</u>

16. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2025 £	2024 £
Trade debtors	12,803	3,923
Other debtors	642	759
Prepayments and accrued income	<u>6,953</u>	<u>5,171</u>
	<u>20,398</u>	<u>9,853</u>

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2025

17.	CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR	2025	2024
		£	£
	Other creditors	<u>7,332</u>	<u>9,022</u>

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

18. MOVEMENT IN FUNDS

	At 1/4/24 £	Net movement in funds £	Transfers between funds £	At 31/3/25 £
Unrestricted funds				
General fund	250,652	67,209	70,815	388,676
Research	10,000	(404)	(1,832)	7,764
Research: Ageing in PWS	98,000	-	(50,000)	48,000
Residential Care Project Manager	2,218	(20)	(2,198)	-
Staff and Trustee Away Day	3,000	-	(3,000)	-
Clinics	2,785	(113)	(2,672)	-
Ageing Research - James Ellis	-	-	2,000	2,000
Community Events - Harrington	-	7,736	(2,117)	5,619
OWL Focus Group - Harrington	-	10,000	-	10,000
Residential Care Project Manager - Harrington	-	23,909	(12,410)	11,499
Engagement and Comms Manager	-	(435)	11,717	11,282
Boss Training	-	(18)	1,500	1,482
Radio 4 Appeal 2025	-	19,348	-	19,348
Report into PWS Deaths	-	-	5,000	5,000
Family Weekends - Crown Holdings	-	(122)	18,000	17,878
Training - Crown Holdings	-	(251)	5,079	4,828
	<u>366,655</u>	<u>126,839</u>	<u>39,882</u>	<u>533,376</u>
Restricted funds				
O.W.L. Group	3,209	(1,558)	-	1,651
Children in Need	9,725	(225)	(9,500)	-
Research - Philip Barnes & Co Ltd	-	1,368	-	1,368
ICAP	447	(33)	(414)	-
Alpkit Foundation	5	(5)	-	-
Awards 4 All	3,162	(835)	-	2,327
Better Breaks Scotland 2023	274	(15)	(259)	-
Postcode Places	19,385	(1,478)	(15,762)	2,145
Northern Ireland	11,102	(3)	-	11,099
TSG Foundation	5,211	-	(5,211)	-
PWSA Funds - The Big Give Campaign	7,586	(7,586)	-	-
The Whitehead Monckton Trust	352	(250)	(102)	-
D'Oyly Carter Charitable Trust	3,160	(1,150)	(1,960)	50
Awards for All	-	14,606	(4,145)	10,461
Better Breaks Scotland 2024	-	2,666	(2,666)	-
Wales - Toyota	-	1,824	-	1,824
Scotlands Events - Inchcape Foundation	-	750	(750)	-
Music Therapy - HKM Charity	-	1,406	-	1,406
New Diagnosis Packs - The Hospital	-	-	-	-
Saturday Fund	-	1,661	(925)	736
Walkover Events UK - Souter Charitable Trust	-	1,000	-	1,000
PWSST - Ageing Research	-	10,843	1,812	12,655
	<u>63,618</u>	<u>22,986</u>	<u>(39,882)</u>	<u>46,722</u>
TOTAL FUNDS	<u>430,273</u>	<u>149,825</u>	<u>-</u>	<u>580,098</u>

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

18. MOVEMENT IN FUNDS - continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	547,174	(479,965)	67,209
Research	-	(404)	(404)
Residential Care Project Manager	-	(20)	(20)
Clinics	-	(113)	(113)
Community Events - Harrington	11,293	(3,557)	7,736
OWL Focus Group - Harrington	10,000	-	10,000
Residential Care Project Manager - Harrington	24,999	(1,090)	23,909
Engagement and Comms Manager	1	(436)	(435)
Boss Training	-	(18)	(18)
Radio 4 Appeal 2025	19,348	-	19,348
Family Weekends - Crown Holdings	-	(122)	(122)
Training - Crown Holdings	-	(251)	(251)
	612,815	(485,976)	126,839
Restricted funds			
O.W.L Group	1	(1,559)	(1,558)
Children in Need	-	(225)	(225)
Research - Philip Barnes & Co Ltd	1,500	(132)	1,368
ICAP	-	(33)	(33)
Alpkit Foundation	-	(5)	(5)
Awards 4 All	-	(835)	(835)
Better Breaks Scotland 2023	-	(15)	(15)
Postcode Places	1	(1,479)	(1,478)
Northern Ireland	-	(3)	(3)
PWSA Funds - The Big Give Campaign	-	(7,586)	(7,586)
The Whitehead Monckton Trust	-	(250)	(250)
D'Oyly Carter Charitable Trust	-	(1,150)	(1,150)
Awards for All	18,073	(3,467)	14,606
Better Breaks Scotland 2024	6,750	(4,084)	2,666
Wales - Toyota	1,824	-	1,824
Scotlands Events - Inchcape Foundation	750	-	750
Music Therapy - HKM Charity	2,000	(594)	1,406
New Diagnosis Packs - The Hospital	-	-	-
Saturday Fund	1,925	(264)	1,661
Walkover Events UK - Souter Charitable Trust	1,000	-	1,000
PWSST - Ageing Research	11,161	(318)	10,843
	44,985	(21,999)	22,986
TOTAL FUNDS	657,800	(507,975)	149,825

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

18. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/4/23 £	Net movement in funds £	Transfers between funds £	At 31/3/24 £
Unrestricted funds				
General fund	236,042	(156)	14,766	250,652
Research	10,000	-	-	10,000
Communications Manager	20,165	(20,165)	-	-
Research: Ageing in PWS	100,000	-	(2,000)	98,000
PWS Siblings project	36,008	-	(36,008)	-
Residential Care Project Manager	-	(7,782)	10,000	2,218
Staff and Trustee Away Day	-	-	3,000	3,000
Clinics	-	(2,215)	5,000	2,785
	402,215	(30,318)	(5,242)	366,655
Restricted funds				
Research	2,195	(2,195)	-	-
O.W.L Group	3,760	(551)	-	3,209
Children in Need	10,000	(275)	-	9,725
Research - Philip Barnes & Co Ltd	88	(5,333)	5,245	-
Familynet Wales & Southwest	1,012	(1,012)	-	-
ICAP	2,924	(2,477)	-	447
Alpkit Foundation	-	5	-	5
Awards 4 All	8,478	(5,316)	-	3,162
Toyota East Midlands	1,292	(494)	(798)	-
Jeans 4 Genes	1,836	(1,836)	-	-
Better Breaks Scotland 2023	-	274	-	274
Toyota	-	(795)	795	-
Postcode Places	-	19,385	-	19,385
Northern Ireland	-	11,102	-	11,102
TSG Foundation	-	5,211	-	5,211
PWSA Funds - The Big Give Campaign	-	7,586	-	7,586
The Whitehead Monckton Trust	-	352	-	352
D'Oyly Carter Charitable Trust	-	3,160	-	3,160
	31,585	26,791	5,242	63,618
TOTAL FUNDS	433,800	(3,527)	-	430,273

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

18. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	419,232	(419,388)	(156)
Communications Manager	-	(20,165)	(20,165)
Residential Care Project Manager	-	(7,782)	(7,782)
Clinics	-	(2,215)	(2,215)
	419,232	(449,550)	(30,318)
Restricted funds			
Research	-	(2,195)	(2,195)
O.W.L Group	1	(552)	(551)
Children in Need	10,000	(10,275)	(275)
Research - Philip Barnes & Co Ltd	1,500	(6,833)	(5,333)
Familynet Wales & Southwest	-	(1,012)	(1,012)
ICAP	1	(2,478)	(2,477)
Alpkit Foundation	420	(415)	5
Awards 4 All	-	(5,316)	(5,316)
Toyota East Midlands	-	(494)	(494)
Jeans 4 Genes	-	(1,836)	(1,836)
Better Breaks Scotland 2023	6,980	(6,706)	274
The Ardwick Trust	200	(200)	-
FB Coates No 4	1,000	(1,000)	-
Toyota	-	(795)	(795)
Postcode Places	24,090	(4,705)	19,385
Thomson Roddick Scottish Auctions	1,761	(1,761)	-
Northern Ireland	11,142	(40)	11,102
TSG Foundation	10,001	(4,790)	5,211
PWSA Funds - The Big Give Campaign	7,586	-	7,586
The Whitehead Monckton Trust	500	(148)	352
D'Oyly Carter Charitable Trust	3,160	-	3,160
	78,342	(51,551)	26,791
TOTAL FUNDS	497,574	(501,101)	(3,527)

Designated Funds as at 31 March 2025

Research - funding for research projects

Research: Ageing in PWS - funding for a specific research project

Residential Care Project Manager - funding for all relevant costs in relation to residential care

Ageing Research - James Ellis - Funding for research into the ageing process and effects on those with PWS

Community Events -Harrington - Funding for all expenses in relation to the cost of organising and executing community events within the UK

OWL Focus Group - Harrington - Funding for all associated costs to enable the OFG members (adults with PWS) to take part in a focus group quarterly both face to face and virtually

Engagement and Comms Manager - Funding for the role of Engagement and Communications Manager and all associated costs to enable fulfilment of their role

Boss Training - Funding towards a project worker to deliver BOSS (Be our successful self) to adults with PWS

Radio 4 Appeal 2025 - Funding towards the cost of operating the helpline

Report into PWS Deaths - Research into premature deaths within the PWS community and why

Family Weekends - Crown Holdings - Funding towards all associated costs to enable the successful organization and execution of all Community Family weekend events

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2025

18. MOVEMENT IN FUNDS - continued

Training - Crown Holdings - Funding towards training costs for staff/volunteers to refresh on essential training and upskill

Restricted Funds as at 31 March 2025

OWL Group - support for meetings and awaydays

Familynet events - funding for family activities

Familynet Cheshire and Hertfordshire - funding for family activities

National Conference 2020 - outsourcing activities - funding for creche facilities

Familynet Essex - funding for family activities

CAF - funding for Support Team and online activities

Awards4 All - funding for diagnosis support

Better Breaks Scotland - for use in Scotland only, for community events/family weekends

Postcode Places - for a new post recruited in January 2024 - volunteer co-ordinator who is taking a lead in all things volunteer related

Northern Ireland - for work to be undertaken within Northern Ireland to reach the community there

TSG Foundation - this is towards a new diagnosis lead in the support teams salary

PWSA Funds - The Big Give Foundation - to develop a resource for the community on how best to control diet within PWS

The Whitehead Monckton Trust - towards any costs relating to the PWS Walkover community event taking part in Hastings in July 2024

D'Oyly Carter Charitable Trust - to be used against any costs against the Dorset Community weekend taking place in September 2024

Wales - Toyota - Funding towards community events within the Wales area only

Scotlands Events - Inchcape Foundation - Funding towards community events within Scotland only

Music Therapy - HKM Charity - Funding towards activities that involve music therapy/sensory activities for those with PWS

New Diagnosis Packs - The Hospital Saturday Fund - Funding towards sensory baskets and information packs for New Diagnosis babies and families

Walkover Events UK - Souter Charitable Trust - Funding towards Walkover community events and all associated costs (an outside activity involving a walk around a country park)

PWSST - Ageing Research - Funding towards Research into the Ageing Process and the effects on those with PWS

19. EMPLOYEE BENEFIT OBLIGATIONS

The total contribution paid to Personal Pension Plans in the year for certain employees amounted to £17,052 (2024: £15,962).

20. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2025.

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

DETAILED STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 MARCH 2025

	2025 £	2024 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	349,236	402,450
Legacies	<u>184,102</u>	<u>-</u>
	533,338	402,450
Other trading activities		
Promotional sales	5,519	4,531
Investment income		
Deposit account interest	16,737	11,416
Charitable activities		
Conferences holidays & support	23,397	20,965
Fundraising events	<u>78,809</u>	<u>58,212</u>
	<u>102,206</u>	<u>79,177</u>
Total incoming resources	657,800	497,574
EXPENDITURE		
Other trading activities		
Fundraising expenditure	17,169	13,798
Charitable activities		
Wages	348,426	359,892
Social security	28,329	30,499
Pensions	17,052	15,962
Insurance	1,631	1,316
Telephone	4,950	4,670
Postage and stationery	4,035	6,451
Printing costs	1,114	5,012
Bank charges	316	419
Events	14,918	10,755
Travel and accommodation	9,420	8,158
Staff training	3,192	3,150
IT costs	17,906	16,495
Office machine maintenance	77	4,757
Subscriptions	4,640	2,738
Projects support	18,956	3,061
Research	<u>8,714</u>	<u>5,875</u>
	483,676	479,210
Support costs		

This page does not form part of the statutory financial statements

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

**DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 MARCH 2025**

	2025 £	2024 £
Support costs		
Management		
Trustees' expenses	501	1,197
Human resources		
Sundries	46	254
Other		
Fixtures and fittings	2,103	2,536
Loss on sale of tangible fixed assets	<u>311</u>	<u>-</u>
	2,414	2,536
Governance costs		
Accountancy and legal fees	<u>4,169</u>	<u>4,106</u>
Total resources expended	<u>507,975</u>	<u>501,101</u>
Net income/(expenditure)	<u>149,825</u>	<u>(3,527)</u>

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