

**REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024
FOR
PRADER-WILLI SYNDROME ASSOCIATION UK CIO**

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

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FOR THE YEAR ENDED 31 MARCH 2024**

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PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2024

The trustees present their report with the financial statements of the charity for the year ended 31 March 2024. 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, conferences, 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 2024 we had 806 members in total (including 345 Members with PWS) which is an increase of almost 8% 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, community days and weekends as well as providing training, and organising conferences and webinars.

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2024

ACHIEVEMENT AND PERFORMANCE

Charitable activities

Trustees agreed several key areas of work for the year 2023 - 24 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.

- Review of website to simplify information with specific area for adults with PWS.

A re-structure and update of the website took place during 2023 which now focuses on three distinct audiences (parents, professionals, and adults with PWS).

- Deliver quarterly webinars on PWS topics.

Four webinars were delivered during the year with 39 attendees. In addition, four Makaton sessions were delivered online with 53 attendees.

- Develop PWS portion size resource.

An expert steering group has been established to oversee the development of the resource. PWSA UK has engaged 'The Nutrition and Diet Resources UK' to project manage the development of the resource which will be available late summer 2024. Funding has been secured for the development and delivery of this resource.

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

The PWSA UK team supported families and professionals throughout the year with 1,154 issues which resulted in 2,738 actions (2% increase) phone calls, letters, and meetings to resolve the issues.

Our prime sources of requests for help were:

- Helpline 35%

- Email 47%

- Facebook: 10%

- Clinics/ Family Net: 2%

- Website: 6%

There were 31 new diagnoses reported to PWSA UK this year and a further 23 possible new diagnoses.

More families are contacting us via email with a modest reduction in the number of calls to the helpline.

PWSA UK delivered 22 training sessions during the year with 290 participants. These training sessions were mainly for professionals working in education and health and social care.

- Develop plan of UK wide events and conferences for key PWS stakeholders.

PWSA UK manages a network of peer-to-peer support groups and networking events across the UK. This includes community days and weekends as well as online peer to peer meetings.

During the year we delivered 69 events with a total of 1147 attendees.

- Define case work and business case to further develop support for PWS community.

Work has started on scoping the key steps for different areas of case work. A small subgroup has been established to oversee this work.

- Feasibility work to define PWS UK role in supporting best standards and quality of life in PWS residential settings.

A fixed term project manager was appointed to scope options as to how PWSA UK could influence standards of care in PWS residential settings. Engagement work has been undertaken with parents, adults with PWS and care home providers. Feasibility work is now looking at several approaches including app-based training for care home staff, a forum for professional carers; and targeted consultancy and training for PWS specialist care home providers.

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

- Listening (Town Hall) events with Chair and CEO for PWSA UK membership.

We held the first Town Hall event in October 2023 with the second one in April 2024. Members joined the Chair of trustees and CEO to hear updates and then share their thoughts on work of the Association. Several areas were discussed including support for older families; support for community events to allow families to network and a desire to know more about clinical trials.

- Review of membership fees to increase engagement with PWS community.

We consulted with the PWSA UK membership, and it was agreed to remove the charge for membership. The aim is to increase engagement through removing any financial barrier to membership. This change came into effect in April 2024 and there has been an increase in the membership numbers of 50 (from 750 to 800).

- Further develop engagement with adults with PWS to ensure their voice is heard.

Working with and supporting adults with PWS has been a key priority across the Association during the year. The OWL (Our Way of Life) group has been promoted and expanded and the first adult conference planned for April 2024.

- Build relationships and share data with key influencing organisations.

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2024

There has been a concerted effort to develop effective working relationships during the year. Partnerships have been developed with FPWR UK, IPWSO, Sibs 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.

- Benchmark reach across UK and target areas of lowest engagement.

A mapping exercise was undertaken to identify lower areas of engagement which identified Scotland, Northern Ireland and London as key areas. During the year we have increased our overall reach by just over 1% but a 2% increase in Scotland, a 5% increase in Northern Ireland and a 2% increase in London.

We have developed plans to increase our engagement in these areas as well as a specific plan for EDI (equality, diversity, and inclusion). Our programs, events and activities are planned in different geographical locations as well as providing a broader range of activities.

- Develop volunteer network to support service delivery and UK reach.

Funding was secured for a part time Volunteer Development Officer who was appointed in January 2024. The aim is to develop robust systems and processes, establish volunteer training and support resulting in an increased pool of volunteers that reflect the PWS community.

- Map PWS specialist clinics and develop outreach.

A Project Manager was appointed for a short period of time to map the PWS clinics across the UK. One of the outcomes is a firm recommendation to establish outreach volunteers to attend all PWS clinics. PWSA UK is now working on plans to recruit and support a UK wide team of outreach clinic volunteers.

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

- Collaborate with key partners including FPWR UK and IPWSO.

This has been a key area of focus for PWSA UK and we have been realigning ourselves with FPWR UK and are committed to working collaboratively on furthering PWS research.

The focus has been on two principal areas, the first being a joint awareness campaign (Move It May) and raising additional funds for ageing research. The second area is working collaboratively to enable the approval and funding of new PWS drugs.

- Establish joint approach to promoting and supporting research.

Through the new partnership with FPWR UK the two organisations (as PWS Stronger Together) are working on plans to promote and support research. This has seen the two organisations meeting with pharmaceuticals and developing plans for PWS community updates and webinars in clinical trials.

6. To sustain the charity.

- Diversify income streams and refresh PWSA UK merchandise offer.

Fundraising remained a challenge with the ongoing cost of living crisis. Plans to diversify income are developing and being tested. The Association has seen some success with match funding, working with corporates and developing donor giving.

Despite the challenging environment the Association saw improved success with applications to trusts and foundations. 23 grants were secured (13 in 2003/4) totalling £184K (£72K in 2003/4).

A new range of merchandise was developed, sourced, and launched. A PWS hidden disability lanyard was also sourced in response to a specific request from the PWS adult group.

- Implement ongoing impact measures and annual impact reporting.

The first PWSA UK Impact report was published which demonstrated the difference made by the Association to the PWS community and how this was achieved. The report was based on an independent Outcomes Evaluation conducted by Insley Consulting Ltd, for which we consulted with 120 people through surveys, focus groups and interviews.

- Board succession planning.

The board undertook a skills audit which identified gaps to inform targeted recruitment. During the year three new trustees were appointed to the board; Dr Evelien Gevers, Consultant Paediatrician and Reader in Endocrinology and Diabetes at Barts Health NHS Trust; Susan Passmore recently retired CEO of PWSA UK; and Rosa Polaschek who has a younger brother with PWS and is a barrister with Doughty Street Chambers. Trustees have agreed plans for ongoing succession planning to ensure continuity and maintaining an effective board.

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2024

ACHIEVEMENT AND PERFORMANCE

Volunteering

The Association has always relied upon the commitment, goodwill, knowledge, and experience of its volunteers. We currently have 31 registered volunteers who organise and support community events and facilitate parent to parent meetings online.

The Association also relies on the goodwill and support of informal volunteers who raise funds, marshal at events, provide specialist skills to the charity, serve as Trustees 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 foundation funding.

We are hugely grateful to the following:

- Tower Bridge International - £4,014.77
- Muriel Jones Foundation - £25,000
- The Ardwick Trust - £200 - (PWS Walkovers)
- Inch Cape Foundation - £750
- F B Coales - £1,000 - (New Diagnosis)
- Alp Kit Foundation - £175 - (Nene Park Walkover)
- Ecclesiastical Insurance Group - £1,000
- Philip Barnes & Co Ltd - £1,500 - (Research)
- Postcode Places - £24,090 - (Volunteer Co Ordinator)
- Augustine Courtauld Trust - £1,500
- TSG Foundation - £10,000 - (New Diagnosis) " Steven Cooper Charitable Trust - £1,000
- The Oak Trust - £750
- Alp Kit Foundation - £245 - (Nene Park Walkover)
- Masonic Charitable Trust - £1,000
- The Whitehead Monckton Trust - £500 - Hastings Walkover
- The James Ellis Charitable Trust - £2,000 (Research)
- Children In Need 2024 - £10,000 - (Support)
- Postcode Lottery - £70,000
- D'Oyly Carte Charitable Trust £3,160 - Dorset Community Weekend

FINANCIAL REVIEW

Financial position

In the financial year under review, the Association received income of £497,574 (2023: £383,383) and incurred expenditure of £501,101 (2023: £518,900) resulting in a deficit on operating activities of £3,527 (2023: deficit £135,517).

Income increased by 30% whilst expenditure decreased by 3% compared with 2022-23.

Total funds as at 31 March 2024 stood at £430,273 (2023: £433,800) of which £63,618 (2023: £31,585) are restricted funds.

Of the remaining funds £116,003 (2023: £166,173) are designated for specific projects.

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.

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2024

FINANCIAL REVIEW

Principal funding sources

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

However, the Association continues to be affected by the reduced levels of disposable income available to support the charitable sector and the continuing squeeze on our costs. 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 in consultation with the Finance Working Group. As of 31st March 2024, 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 £116,003. 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 2024 is £250,652 which represents 6 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.

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2024

FUTURE PLANS

Strategic Objectives for 2024 -5

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 2024 - 25.

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

1.1 Information

- Review of website for medium to longer term development
- PWSA magazine to be sent out electronically.
- Review of communications and engagement.
- Produce and distribute the 'PWS Portion Size' booklet.
- Produce and distribute 'consensus' best practice guidance.
- Research information requirements for adults with PWS.

1.2 Training

- Increase and promote face to face and 'live' online training for those supporting people living with PWS.
- Review the online PWS Academy and decide on its long-term viability.
- Pilot and roll out the BOSS (Build our Social Skills) training for adults with PWS.
- Increase delivery of Makaton training to support the PWS community.
- Research options for accredited training for professional care givers.

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

- Deliver a diverse program of community events and weekends that meet the needs of the PWS community.
- Pilot a revised approach to PWS conferences
- Facilitate a parent-to-parent forum for parents of ageing adults with PWS.
- Facilitate a parent-to-parent forum for parents of individuals for mUPD subtype of PWS.
- Continue to develop and pilot strategies to improve standards in residential settings with a focus on training, support and working with care providers.

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

- Town Hall event will be held every 6 months and other opportunities to engage and listen to the PWS community.
- Systematic gathering and review of trends and issues presenting to PWSA UK
- Increase engagement with adults with PWS through the OWL group and adult conference.
- Enable a wider membership through increased engagement and increase numbers of registered members.
- Increase engagement with key stakeholders and partners to increase the influence and impact of PWSA UK

4. To develop and maintain regional reach.

- Undertake a mapping exercise on an annual basis to assess changes to our reach and engagement.
- Secure funding and appoint in-country PWS support workers for Northern Ireland and Scotland.
- Delivery of EDI plans
- Increase the number of active volunteers to support fundraising, raising profile, outreach at clinics, feeding back on local services, peer to peer support and buddying, providing support for local events and networking opportunities.
- Increasing our attendance at PWS clinics through recruitment and training of volunteers.

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

- Deliver updates on PWS research for the community in partnership with FPWR UK and IPWSO.
- Deliver a joint campaign with FPWR UK to raise additional funds for ageing research.
- Promote opportunities for participation in research and clinical trials.
- Establish funding criterion for surveys, reviews, and studies.

6. To sustain the charity.

6.1 Governance

- Continue with succession planning for the board and developing a recruitment plan based on skills gaps.
- Ensure that M&E (monitoring and evaluation) and demonstrating impact are embedded into PWSA UK.
- Review of IT requirements with a focus on CRM and cyber security.

6.2 Financial Management

- Diversify income through sales of our new merchandise range; promoting legacies; developing opportunities for match funding; establishing joint fundraising for research with FPWR UK; creating relationships with corporates and pharmaceuticals; focusing on regular and major donors; and increasing income from training and consultancy.

**REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2024**

6.3 Staffing

- Review of core staff with the aim of reducing fixed costs.
- Review and update of staff handbook, staff policies and procedures, T&Cs and staff employment contracts.
- Review and refresh PWSA UK values and embed across the charity.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust and constitutes an unincorporated charity.

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.

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 2024

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number
1155846

Principal address

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

Trustees

Royal Patron

HRH The Princess Michael of Kent

Patron

Prof Tony Holland CBE

Trustees

Lt Col Danny Leslie (Chairman)
Matthew Christensen (Treasurer)
Andrew Abbott
Catherine Carey
Dr Robin Chung
Dr Evelien Gevers (November 2023)
Anne Good
Dr Anne Livesey
Ian Metcalf
Susan Passmore (November 2023)
Rosa Polaschek (November 2023)
Karen Potts
Stephanie Sokolowski

**Chief Executive and
Honorary Secretary**

Jackie Lodge

Independent Examiner

Johnson Tidsall Limited
Chartered Accountants
81 Burton Road
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Bankers

HSBC Bank Plc
1 St Peters Street
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Derbyshire
DE1 2AE

Approved by order of the board of trustees on19/10/2024..... 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 2024.

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
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Derbyshire
DE1 1TJ

Date: 24/10/2024

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 MARCH 2024

	Notes	Unrestricted funds £	Restricted funds £	2024 Total funds £	2023 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	3	324,108	78,342	402,450	298,683
Charitable activities					
Charitable activities	6	79,177	-	79,177	77,864
Other trading activities	4	4,531	-	4,531	5,217
Investment income	5	11,416	-	11,416	1,619
Total		419,232	78,342	497,574	383,383
EXPENDITURE ON					
Raising funds		12,083	1,715	13,798	11,738
Charitable activities					
Charitable activities	7	437,468	49,835	487,303	507,162
Total		449,551	51,550	501,101	518,900
NET INCOME/(EXPENDITURE)					
Transfers between funds	17	(30,319) (5,242)	26,792 5,242	(3,527) -	(135,517) -
Net movement in funds		(35,561)	32,034	(3,527)	(135,517)
RECONCILIATION OF FUNDS					
Total funds brought forward		402,215	31,585	433,800	569,317
TOTAL FUNDS CARRIED FORWARD		366,654	63,619	430,273	433,800

The notes form part of these financial statements

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

BALANCE SHEET

31 MARCH 2024

	Notes	Unrestricted funds £	Restricted funds £	2024 Total funds £	2023 Total funds £
FIXED ASSETS					
Tangible assets	13	3,598	-	3,598	2,874
CURRENT ASSETS					
Stocks	14	4,186	-	4,186	3,189
Debtors	15	9,853	-	9,853	4,763
Cash at bank and in hand		<u>358,040</u>	<u>63,618</u>	<u>421,658</u>	<u>445,636</u>
		372,079	63,618	435,697	453,588
CREDITORS					
Amounts falling due within one year	16	(9,022)	-	(9,022)	(22,662)
NET CURRENT ASSETS		<u>363,057</u>	<u>63,618</u>	<u>426,675</u>	<u>430,926</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>366,655</u>	<u>63,618</u>	<u>430,273</u>	<u>433,800</u>
NET ASSETS		<u>366,655</u>	<u>63,618</u>	<u>430,273</u>	<u>433,800</u>
FUNDS	17				
Unrestricted funds				366,655	402,215
Restricted funds				<u>63,618</u>	<u>31,585</u>
TOTAL FUNDS				<u>430,273</u>	<u>433,800</u>

The financial statements were approved by the Board of Trustees and authorised for issue on ...19/10/2024..... and were signed on its behalf by:



D Leslie - Trustee



M Christensen - Trustee

The notes form part of these financial statements

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

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. Total per financial statements £35,669.

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.

**NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2024**

2. ACCOUNTING POLICIES - continued

Income

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

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 2024

2. ACCOUNTING POLICIES - continued

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

	2024 £	2023 £
Donations	402,450	263,014
Legacies	-	35,669
	<u>402,450</u>	<u>298,683</u>

4. OTHER TRADING ACTIVITIES

	2024 £	2023 £
Promotional sales	<u>4,531</u>	<u>5,217</u>

5. INVESTMENT INCOME

	2024 £	2023 £
Deposit account interest	<u>11,416</u>	<u>1,619</u>

6. INCOME FROM CHARITABLE ACTIVITIES

	Activity	2024 £	2023 £
Conferences holidays & support	Charitable activities	20,965	16,437
Fundraising events	Charitable activities	<u>58,212</u>	<u>61,427</u>
		<u>79,177</u>	<u>77,864</u>

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2024

7. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 8) £	Support costs (see note 9) £	Totals £
Charitable activities	<u>479,210</u>	<u>8,093</u>	<u>487,303</u>

8. DIRECT COSTS OF CHARITABLE ACTIVITIES

	2024 £	2023 £
Staff costs	406,353	342,905
Insurance	1,316	1,276
Telephone	4,670	5,670
Postage and stationery	6,451	7,086
Printing costs	5,012	5,262
Bank charges	419	402
Events	10,755	25,794
Travel and accommodation	8,158	10,134
Family weekend	-	1,473
Staff training	3,150	1,265
IT costs	16,495	12,481
Office machine maintenance	4,757	4,591
Subscriptions	2,738	2,846
Projects support	3,061	51,465
Research	5,875	25,218
	<u>479,210</u>	<u>497,868</u>

9. SUPPORT COSTS

	Management £	Human resources £	Other £	Governance costs £	Totals £
Charitable activities	<u>1,197</u>	<u>254</u>	<u>2,536</u>	<u>4,106</u>	<u>8,093</u>

Accountancy and legal fees include £3,300 in respect of the Independent Examination fee.

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

	2024 Charitable activities £	2023 Total activities £
Trustees' expenses	1,197	2,345
Sundries	254	477
Depreciation of tangible fixed assets	2,536	1,908
Loss on sale of tangible fixed assets	-	142
Accountancy and legal fees	4,106	4,422
	<u>8,093</u>	<u>9,294</u>

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2024

10. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2024 nor for the year ended 31 March 2023.

Trustees' expenses

	2024	2023
	£	£
Trustees' expenses	<u>1,197</u>	<u>2,345</u>

Trustees' expenses relate to attendance at meeting costs.

11. STAFF COSTS

	2024	2023
	£	£
Wages and salaries	359,892	303,786
Social security costs	30,499	27,265
Other pension costs	<u>15,962</u>	<u>11,854</u>
	<u>406,353</u>	<u>342,905</u>

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

	2024	2023
Charitable activities	9	8
Management and administration	<u>1</u>	<u>1</u>
	<u>10</u>	<u>9</u>

No employees received emoluments in excess of £60,000.

During the year one employee (2023 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 £89,173 (2023: £77,603).

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	226,878	71,805	298,683
Charitable activities			
Charitable activities	77,864	-	77,864
Other trading activities	5,217	-	5,217
Investment income	<u>1,619</u>	<u>-</u>	<u>1,619</u>
Total	<u>311,578</u>	<u>71,805</u>	<u>383,383</u>
EXPENDITURE ON			
Raising funds	9,805	1,933	11,738

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2024

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted funds £	Restricted funds £	Total funds £
Charitable activities			
Charitable activities	<u>407,660</u>	<u>99,502</u>	<u>507,162</u>
Total	<u>417,465</u>	<u>101,435</u>	<u>518,900</u>
NET INCOME/(EXPENDITURE)			
Transfers between funds	(105,887) <u>44</u>	(29,630) <u>(44)</u>	(135,517) <u>-</u>
Net movement in funds	(105,843)	(29,674)	(135,517)
RECONCILIATION OF FUNDS			
Total funds brought forward	<u>508,058</u>	<u>61,259</u>	<u>569,317</u>
TOTAL FUNDS CARRIED FORWARD	<u>402,215</u>	<u>31,585</u>	<u>433,800</u>

13. TANGIBLE FIXED ASSETS

	Fixtures and fittings £
COST	
At 1 April 2023	<u>22,629</u>
Additions	<u>3,260</u>
At 31 March 2024	<u>25,889</u>
DEPRECIATION	
At 1 April 2023	<u>19,755</u>
Charge for year	<u>2,536</u>
At 31 March 2024	<u>22,291</u>
NET BOOK VALUE	
At 31 March 2024	<u>3,598</u>
At 31 March 2023	<u>2,874</u>

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2024

14. STOCKS

	2024	2023
	£	£
Finished goods	<u>4,186</u>	<u>3,189</u>

15. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Trade debtors	3,923	-
Other debtors	759	698
Prepayments and accrued income	<u>5,171</u>	<u>4,065</u>
	<u>9,853</u>	<u>4,763</u>

16. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Other creditors	<u>9,022</u>	<u>22,662</u>

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2024

17. 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
	<u>402,215</u>	<u>(30,318)</u>	<u>(5,242)</u>	<u>366,655</u>
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
	<u>31,585</u>	<u>26,791</u>	<u>5,242</u>	<u>63,618</u>
TOTAL FUNDS	<u>433,800</u>	<u>(3,527)</u>	<u>-</u>	<u>430,273</u>

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2024

17. 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	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)

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2024

17. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/4/22 £	Net movement in funds £	Transfers between funds £	At 31/3/23 £
Unrestricted funds				
General fund	280,878	(44,836)	-	236,042
Research	19,956	(10,000)	44	10,000
Communications Manager	57,224	(37,059)	-	20,165
Research: Ageing in PWS	100,000	-	-	100,000
PWS Siblings project	50,000	(13,992)	-	36,008
	508,058	(105,887)	44	402,215
Restricted funds				
Research	1,924	-	271	2,195
O.W.L Group	3,981	(221)	-	3,760
Children in Need	23	9,977	-	10,000
Research - Philip Barnes & Co Ltd	4,361	(4,273)	-	88
Research Rokeby School	315	-	(315)	-
Familynet events	767	(767)	-	-
Familynet Wales & Southwest	1,938	(926)	-	1,012
Familynet Cheshire & Hertfordshire	1,000	(1,000)	-	-
National Conference 2020 - Outsourcing activities	1,576	(1,576)	-	-
National Conference 2020	709	(709)	-	-
Familynet Essex	1,414	(1,414)	-	-
CAF	33,431	(33,431)	-	-
ICAP	7,320	(4,396)	-	2,924
St James's Place	2,500	(2,500)	-	-
Awards 4 All	-	8,478	-	8,478
Toyota East Midlands	-	1,292	-	1,292
Jeans 4 Genes	-	1,836	-	1,836
	61,259	(29,630)	(44)	31,585
TOTAL FUNDS	<u>569,317</u>	<u>(135,517)</u>	<u>-</u>	<u>433,800</u>

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2024

17. 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	311,578	(356,414)	(44,836)
Research	-	(10,000)	(10,000)
Communications Manager	-	(37,059)	(37,059)
PWS Siblings project	-	(13,992)	(13,992)
	311,578	(417,465)	(105,887)
Restricted funds			
O.W.L Group	-	(221)	(221)
Children in Need	20,000	(10,023)	9,977
Hospital Saturday fund	2,000	(2,000)	-
Research - Philip Barnes & Co Ltd	1,500	(5,773)	(4,273)
Familynet events	-	(767)	(767)
Familynet Wales & Southwest	-	(926)	(926)
Familynet Cheshire & Hertfordshire	-	(1,000)	(1,000)
National Conference 2020 - Outsourcing activities	-	(1,576)	(1,576)
National Conference 2020	-	(709)	(709)
Familynet Essex	-	(1,414)	(1,414)
Masonic Charitable Trust	5,000	(5,000)	-
CAF	26,087	(59,518)	(33,431)
ICAP	1	(4,397)	(4,396)
A Clark Automobiles	1,000	(1,000)	-
St James's Place	-	(2,500)	(2,500)
Boshier Hinton Foundation	2,000	(2,000)	-
Awards 4 All	9,925	(1,447)	8,478
Toyota East Midlands	1,292	-	1,292
Jeans 4 Genes	3,000	(1,164)	1,836
	71,805	(101,435)	(29,630)
TOTAL FUNDS	<u>383,383</u>	<u>(518,900)</u>	<u>(135,517)</u>

Designated Funds as at 31 March 2024

Research - funding for research projects
Research: Ageing in PWS - funding for a specific research project
Residential Care Project Manager
Staff and Trustee Away Day
Clinics

Restricted Funds as at 31 March 2024

OWL Group - support for meetings and awaydays
Children in Need - Funding for a member of Support Team
Research Rokeby - funding for research projects
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
ICAP - funding for family activities
A Clark Automobiles - PWS animation project

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2024

17. MOVEMENT IN FUNDS - continued

St James's Place - funding for animation videos

Awards4 All - funding for diagnosis support

Alpkit Foundation - for use for community event at Nene Park

Better Breaks Scotland 2023 - 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

Transfers between funds

Transfers represent reallocation between various research grants.

18. EMPLOYEE BENEFIT OBLIGATIONS

The total contribution paid to Personal Pension Plans in the year for certain employees amounted to £15,962 (2023: £11,854).

19. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2024.