

**REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023
FOR
PRADER-WILLI SYNDROME ASSOCIATION UK CIO**

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

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FOR THE YEAR ENDED 31 MARCH 2023**

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PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2023

The Trustees of Prader-Willi Syndrome Association UK CIO (PWSA UK) present their report with the financial statements of the charity for the year ended 31 March 2023. 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

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 there is currently a modest membership subscription for families and professionals, and free to all people over 18 with PWS.

On 31st March 2023 we had 424 Subscribed Members and 323 Members with PWS.

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.

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2023

ACHIEVEMENT AND PERFORMANCE

1. To achieve sustainable growth

With the cost-of-living crisis, charities are facing significant financial challenges, and this is true for PWSA UK with reduced income and increased costs. Previous legacy income has sustained the charity, but this is an uncertain income stream. Going forward the Association will need to diversify its income streams to ensure it is able to achieve its strategic objectives.

The Association secured funding from Charities Aid Foundation (CAF) to develop an impact framework. This work is ongoing and a report setting out the impact of PWSA UK's work will be available from late 2023. This is a key project to enable the Association to demonstrate the positive difference it makes to the PWS community.

2. To be the number one knowledge and information hub for PWS in the UK

We constantly review and update all our information and publications. Information and online resources are constantly being updated and gaps in information identified and filled.

Staff continue to attend PWS Specialist Clinics offering support and advice to families at locations across the UK. We continue to look at ways to increase our reach and ensure outreach at all locations.

PWSA UK delivered 20 training sessions during the year with 239 participants.

The PWSA UK Conference which was postponed twice due to Covid-19 restrictions went ahead over the weekend of 4th and 5th March 2023. 161 people attended the conference in Derbyshire with a full schedule of talks and events over 2 days.

3. To provide the best possible support to those living with PWS and their families and carers

The PWSA UK team supported families and professionals throughout the year with 1,071 issues which resulted in 2,682 actions (16% increase) phone calls, letters and meetings to resolve the issues. Support varies from practical advice, information, letters of support, mediation and attending meetings on families' behalf with professionals such as social workers, teaching staff and medical professionals. The number of queries is increasing as is the complexity of the issues being dealt with.

Our prime sources of requests for help were:

- Helpline: 42%
- Email: 39%
- Facebook: 7%
- Clinics/ Family Net: 2%
- Website: 10%

There were 40 new diagnoses reported to PWSA UK this year (an increase of 5) and a further 29 (an increase of 4) possible new diagnoses.

4. To maintain regional reach through its volunteer groups

Familynet (renamed as community days and weekends), is our network of peer to-peer support groups throughout the UK providing local social events, meetings, and support to the wider PWS community. During the year we delivered 72 events with a total of 1,152 attendees.

5. To be the voice for those affected by PWS

We continue to interact with our community and members through Facebook, Twitter and Instagram. We saw modest increases in all areas. In March 2023 we had 5,931 followers on Facebook, 1,465 Twitter followers and 1,108 followers on Instagram. Our closed Facebook Group for UK families is called PWSA UK Community Hub - Empowering Life with PWS and it has 673 members. We also host a closed group for siblings called PWSA UK - Sibs Hub which has 38 members. Social Media continues to be an important means of communication for our families and the Association continues to expand its communication through these platforms.

PWSA UK is increasing its work with adults with PWS and supports the OWL (Our Way of Life) group. The group meets regularly and has an annual conference. PWSA UK works with the group to develop and circulate a quarterly newsletter.

6. To support and promote research into the management and alleviation of PWS

PWSA UK continues to work with Pharmaceutical Companies interested in bringing trials to the UK with the aim that UK families will have opportunities to take part in these trials. We continue to provide information on up-to-date research to the PWS community. During 2022-23 PWSA UK commissioned a study into the needs of siblings of people with PWS. The University of East Anglia worked with siblings and produced a report outlining recommendations as to how PWSA UK can develop its information and support for siblings.

**REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2023**

ACHIEVEMENT AND PERFORMANCE - continued

Volunteering

The Association has always relied upon the commitment, goodwill, knowledge, and experience of its volunteers. We currently have 18 registered volunteers who organise and support community events.

The Association also relies on the goodwill and support of informal volunteers who raise funds, marshal at events, provide advice 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.

We are also very grateful to the following:

- Muriel Jones Foundation - £25,000
- The Masonic Charitable Foundation - £5,000 per year for three years
- The Ecclesiastical Movement for Good - £1,000
- Children in Need - £10,000 per year for three years
- Philip Barnes & Co - £1,500 (research)
- The Hospital Saturday Fund - £2,000 (PWS Animation Videos)
- Arnold Clark Automobiles - £1,000
- Boshier Hinton Foundation - £2,000 (PWS Animation Videos)
- Augustine Courtauld Charitable Foundation £1,000 (National Conference)
- CAF - £10,000 (Impact Assessment project)
- Awards For All - £9,925 (New Diagnosis Support)
- Jeans 4 Genes - £3,000
- The Oak Trust and Toyota Derby - £1,292 (East Midlands Community Events)

Grants and legacies not only enable us to continue our work with our PWS community but enable us to expand and increase the services that we offer in the future.

FINANCIAL REVIEW

Financial position

In the financial year under review, the Association received income of £383,383 (2022: £361,569) and incurred expenditures of £518,900 (2022: £364,343) resulting in a deficit on operating activities of £135,517 (2022: £2,774).

Income increased by 6% whilst expenditure increased by 42% compared with 2021-2022.

Total funds as at 31 March 2023 stood at £433,800 (2022: £569,317) of which £31,585 (2022: £61,259) are restricted funds.

Of the remaining funds £166,173 (2022: £227,180) 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.

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 will seek to diversify income sources over the coming years.

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2023

FINANCIAL REVIEW - continued

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 2023, all reserves were held in the bank deposit account. 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 £166,173. 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 31 March 2023 is £236,042 which represents 8 months of unrestricted operating costs. Whilst this is higher than the 6 months target, the Trustees have agreed a deficit budget for the year 2023/24 which projects that the reserves will fall to below the target 6 months within the year.

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.

FUTURE PLANS

Strategic Objectives for 2023 - 24

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 2023 - 24.

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

- Review of website to simplify information with specific area for adults with PWS.
- Deliver quarterly webinars on PWS topics.
- Develop PWS portion size resources.

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

- Develop plan of UK wide events and conferences for key PWS stakeholders.
- Define case work and business case to further develop support for PWS community.
- Feasibility work to define PWS UK role in supporting best standards and quality of life in PWS residential settings.

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

- Listening (Town Hall) events with Chair and CEO for PWSA UK membership.
- Review of membership fees to increase engagement with PWS community.
- Further develop engagement with adults with PWS to ensure their voice is heard.
- Build relationships and share data with key influencing organisations.

4. To develop and maintain regional reach.

- Benchmark reach across UK and target areas of lowest engagement.
- Develop volunteer network to support service delivery and UK reach.
- Map PWS specialist clinics and develop outreach.

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.
- Establish joint approach to promoting and supporting research.

6. To sustain the charity.

- Diversify income streams and refresh PWSA UK merchandise offer.
- Implement ongoing impact measures and annual impact reporting.
- Board succession planning.

Trustees will work on plans during the year for the period 2024 - 2025.

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 MARCH 2023

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, Treasurer and Secretary 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. Trustees are provided with a comprehensive induction pack and training with NCVO. Following a period as a 'candidate' Trustee, the prospective Trustee will be considered for election at a subsequent AGM.

During the year 2022/23 the Trustee Board operated a sub-committee structure of working groups to best use the diverse skills of its members; these working groups were:

- Adults Working Group
- Communications Working Group
- Finance and Fundraising Working Group
- Information and Training Working Group
- Research Working Group
- Service Delivery Working Group

The working groups 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 2023

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

Royal Patron

HRH The Princess Michael of Kent

Patron

Prof Tony Holland BSc, MBBS, MRCP,
FRCPsych, MPhil,
Dipl Hum Clin Genet

Trustees

Danny Leslie (Chairman)	
Matthew Christensen (Treasurer)	
Andrew Abbott	appointed 26 November 2022
Catherine Carey	
Flynn Castles	stood down 16 March 2023
Robin Chung	
Anne Good	
Anne Livesey	
Ian Metcalf	
Susan Passmore	appointed 1 April 2023
Karen Potts	
Stefania Rosso	stood down 16 March 2023
Stephanie Sokolowski	

**Chief Executive and
Honorary Secretary**

Susan Passmore	until 31 March 2023
Jackie Lodge	from 1 April 2023

Independent Examiner

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

Bankers

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

Approved by order of the board of trustees on 18 November 2023 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 2023.

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 FCA

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

Date: 28 November 2023

ADER-WILLI SYNDROME ASSOCIATION UK CIO

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 MARCH 2023

	Notes	Unrestricted funds £	Restricted funds £	2023 Total funds £	2022 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	3	226,878	71,805	298,683	304,784
Charitable activities	6				
Charitable activities		77,864	-	77,864	49,345
Other trading activities	4	5,217	-	5,217	7,394
Investment income	5	1,619	-	1,619	46
Total		<u>311,578</u>	<u>71,805</u>	<u>383,383</u>	<u>361,569</u>
EXPENDITURE ON					
Raising funds		9,805	1,933	11,738	16,722
Charitable activities	7				
Charitable activities		407,660	99,502	507,162	347,621
Total		<u>417,465</u>	<u>101,435</u>	<u>518,900</u>	<u>364,343</u>
NET INCOME/(EXPENDITURE)					
Transfers between funds	17	(105,887) 44	(29,630) (44)	(135,517) -	(2,774) -
Net movement in funds		(105,843)	(29,674)	(135,517)	(2,774)
RECONCILIATION OF FUNDS					
Total funds brought forward		508,058	61,259	569,317	572,091
TOTAL FUNDS CARRIED FORWARD		<u>402,215</u>	<u>31,585</u>	<u>433,800</u>	<u>569,317</u>

The notes form part of these financial statements

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

BALANCE SHEET 31 MARCH 2023

	Notes	Unrestricted funds £	Restricted funds £	2023 Total funds £	2022 Total funds £
FIXED ASSETS					
Tangible assets	13	2,874	-	2,874	2,417
CURRENT ASSETS					
Stocks	14	3,189	-	3,189	3,382
Debtors	15	4,763	-	4,763	39,810
Cash at bank and in hand		<u>408,806</u>	<u>36,830</u>	<u>445,636</u>	<u>539,329</u>
		416,758	36,830	453,588	582,521
CREDITORS					
Amounts falling due within one year	16	(17,417)	(5,245)	(22,662)	(15,621)
NET CURRENT ASSETS		<u>399,341</u>	<u>31,585</u>	<u>430,926</u>	<u>566,900</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>402,215</u>	<u>31,585</u>	<u>433,800</u>	<u>569,317</u>
NET ASSETS		<u>402,215</u>	<u>31,585</u>	<u>433,800</u>	<u>569,317</u>
FUNDS	17				
Unrestricted funds				402,215	508,058
Restricted funds				<u>31,585</u>	<u>61,259</u>
TOTAL FUNDS				<u>433,800</u>	<u>569,317</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 18 November 2023 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 2023**

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.

Debtors

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

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2023

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.

Reserves

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

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2023

2. ACCOUNTING POLICIES - continued

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

	2023	2022
	£	£
Donations	263,014	290,372
Legacies	35,669	14,412
	<u>298,683</u>	<u>304,784</u>

4. OTHER TRADING ACTIVITIES

	2023	2022
	£	£
Promotional sales	<u>5,217</u>	<u>7,394</u>

5. INVESTMENT INCOME

	2023	2022
	£	£
Deposit account interest	<u>1,619</u>	<u>46</u>

6. INCOME FROM CHARITABLE ACTIVITIES

	Activity	2023	2022
		£	£
Conferences holidays & support	Charitable activities	16,437	16,660
Fundraising events	Charitable activities	<u>61,427</u>	<u>32,685</u>
		<u>77,864</u>	<u>49,345</u>

7. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 8)	Support costs (see note 9)	Totals
	£	£	£
Charitable activities	<u>497,868</u>	<u>9,294</u>	<u>507,162</u>

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2023

8. DIRECT COSTS OF CHARITABLE ACTIVITIES

	2023 £	2022 £
Staff costs	342,905	265,155
Other operating leases	-	1,258
Insurance	1,276	1,211
Telephone	5,670	5,691
Postage and stationery	7,086	7,052
Printing costs	5,262	7,790
AIM management costs	-	386
Bank charges	402	282
Events	25,794	4,343
Travel and accommodation	10,134	7,024
Family weekend	1,473	1,796
Staff training	1,265	2,748
IT costs	12,481	10,703
Office machine maintenance	4,591	4,449
Subscriptions	2,846	3,850
Projects support	51,465	-
Research	25,218	10,498
	<u>497,868</u>	<u>334,236</u>

9. SUPPORT COSTS

	Management £	Human resources £	Other £	Governance costs £	Totals £
Charitable activities	<u>2,345</u>	<u>477</u>	<u>2,050</u>	<u>4,422</u>	<u>9,294</u>

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

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

	2023 Charitable activities £	2022 Total activities £
Trustees' expenses	2,345	2,396
Sundries	477	3,140
Depreciation of tangible fixed assets	1,908	1,465
Loss on sale of tangible fixed assets	142	-
Auditors' remuneration	-	4,932
Accountancy and legal fees	4,422	1,452
	<u>9,294</u>	<u>13,385</u>

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2023

10. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2023 nor for the year ended 31 March 2022.

Trustees' expenses

	2023	2022
	£	£
Trustees' expenses	<u>2,345</u>	<u>2,396</u>

Trustees' expenses relate to attendance at meeting costs.

11. STAFF COSTS

	2023	2022
	£	£
Wages and salaries	303,786	236,463
Social security costs	27,265	19,459
Other pension costs	<u>11,854</u>	<u>9,233</u>
	<u>342,905</u>	<u>265,155</u>

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

	2023	2022
		
Charitable activities	8	7
Management and administration	<u>1</u>	<u>1</u>
	<u>9</u>	<u>8</u>

During the year one employee (2022 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 £72,191 (2022: £63,945).

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	209,056	95,728	304,784
Charitable activities			
Charitable activities	49,345	-	49,345
Other trading activities	7,394	-	7,394
Investment income	<u>46</u>	<u>-</u>	<u>46</u>
Total	<u>265,841</u>	<u>95,728</u>	<u>361,569</u>
EXPENDITURE ON			
Raising funds	11,725	4,997	16,722
Charitable activities			
Charitable activities	<u>250,862</u>	<u>96,759</u>	<u>347,621</u>
Total	262,587	101,756	364,343

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2023

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted funds £	Restricted funds £	Total funds £
NET INCOME/(EXPENDITURE)	3,254	(6,028)	(2,774)
Transfers between funds	<u>2,366</u>	<u>(2,366)</u>	<u>-</u>
Net movement in funds	5,620	(8,394)	(2,774)
RECONCILIATION OF FUNDS			
Total funds brought forward	502,438	69,653	572,091
TOTAL FUNDS CARRIED FORWARD	<u><u>508,058</u></u>	<u><u>61,259</u></u>	<u><u>569,317</u></u>

13. TANGIBLE FIXED ASSETS

	Fixtures and fittings £
COST	
At 1 April 2022	20,442
Additions	2,507
Disposals	<u>(320)</u>
At 31 March 2023	<u><u>22,629</u></u>
DEPRECIATION	
At 1 April 2022	18,025
Charge for year	1,908
Eliminated on disposal	<u>(178)</u>
At 31 March 2023	<u><u>19,755</u></u>
NET BOOK VALUE	
At 31 March 2023	<u><u>2,874</u></u>
At 31 March 2022	<u><u>2,417</u></u>

14. STOCKS

	2023 £	2022 £
Finished goods	<u><u>3,189</u></u>	<u><u>3,382</u></u>

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2023

15. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023 £	2022 £
Trade debtors	-	35,000
Other debtors	698	933
Prepayments and accrued income	<u>4,065</u>	<u>3,877</u>
	<u>4,763</u>	<u>39,810</u>

16. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023 £	2022 £
Trade creditors	-	90
Other creditors	<u>22,662</u>	<u>15,531</u>
	<u>22,662</u>	<u>15,621</u>

17. 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	<u>50,000</u>	<u>(13,992)</u>	-	<u>36,008</u>
	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
	<u>61,259</u>	<u>(29,630)</u>	<u>(44)</u>	<u>31,585</u>
TOTAL FUNDS	<u>569,317</u>	<u>(135,517)</u>	-	<u>433,800</u>

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2023

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	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	383,383	(518,900)	(135,517)

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2023

17. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/4/21 £	Net movement in funds £	Transfers between funds £	At 31/3/22 £
Unrestricted funds				
General fund	396,565	46,947	(162,634)	280,878
Research	15,000	(10,044)	15,000	19,956
Communications Manager	90,872	(33,648)	-	57,224
Research: Ageing in PWS	-	-	100,000	100,000
PWS Siblings project	-	-	50,000	50,000
	502,437	3,255	2,366	508,058
Restricted funds				
Research	2,239	(315)	-	1,924
O.W.L Group	4,642	(661)	-	3,981
Computer equipment	2,366	-	(2,366)	-
Children in Need	600	(577)	-	23
Familynet West Midlands	28	(28)	-	-
Research - Philip Barnes & Co Ltd	3,000	1,361	-	4,361
Research Rokeby School	315	-	-	315
Familynet events	2,427	(1,660)	-	767
Familynet Wales & Southwest	2,478	(540)	-	1,938
Familynet Cheshire & Hertfordshire	1,000	-	-	1,000
National Conference 2020 - Outsourcing activities	2,000	(424)	-	1,576
National Conference 2020	709	-	-	709
Familynet Essex	1,500	(86)	-	1,414
Garfield Weston Foundation	4,462	(4,462)	-	-
CAF	1,300	32,131	-	33,431
ICAP	40,588	(33,268)	-	7,320
St James's Place	-	2,500	-	2,500
	69,654	(6,029)	(2,366)	61,259
TOTAL FUNDS	572,091	(2,774)	-	569,317

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 MARCH 2023

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	265,841	(218,894)	46,947
Research	-	(10,044)	(10,044)
Communications Manager	-	(33,648)	(33,648)
	265,841	(262,586)	3,255
Restricted funds			
Research	-	(315)	(315)
O.W.L Group	-	(661)	(661)
Children in Need	-	(577)	(577)
Familynet West Midlands	-	(28)	(28)
Research - Philip Barnes & Co Ltd	1,500	(139)	1,361
Familynet events	-	(1,660)	(1,660)
Familynet Wales & Southwest	-	(540)	(540)
National Conference 2020 - Outsourcing activities	-	(424)	(424)
Familynet Essex	-	(86)	(86)
Garfield Weston Foundation	-	(4,462)	(4,462)
Masonic Charitable Trust	5,000	(5,000)	-
CAF	58,261	(26,130)	32,131
ICAP	-	(33,268)	(33,268)
A Clark Automobiles	500	(500)	-
P Sowerby Foundation	9,116	(9,116)	-
Alpkit Foundation	150	(150)	-
Postcode Lottery	18,701	(18,701)	-
St James's Place	2,500	-	2,500
	95,728	(101,757)	(6,029)
TOTAL FUNDS	<u>361,569</u>	<u>(364,343)</u>	<u>(2,774)</u>

Designated Funds as at 31 March 2023

Research - funding for research projects
Communications Manager - 3 year funding for a Communications manager post
Research: Ageing in PWS - funding for a specific research project
PWS Siblings project - specific research

Restricted Funds as at 31 March 2023

Research - Funding for research projects
OWL Group - support for meetings and awaydays
Children in Need - Funding for a member of Support Team
Research Philip Barnes - funding for research projects
Research Rokeby - funding for research projects
Familynet events - funding for family activities
Familynet Wales and S West - 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
St James's Place - funding for animation videos
Awards 4 All - funding for diagnosis support
Toyota East Midlands - funding for East Midlands events
Jeans 4 Genes - funding for diagnosis support

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2023

17. MOVEMENT IN FUNDS - continued

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 £11,854 (2022: £9,233).

19. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2023.