PRADER-WILLI SYNDROME ASSOCIATION UK

England & Wales · Charity number 1155846

Details

Other names	PWSA UK
Status	Registered
Legal form	CIO
Registered	2014-02-19
Register	View on the Charity Commission register

Contact

Address	Pwsa UK c/o Metcalf Commercial Decorators 3 Deer Park Road Moulton Park Industrial Estate Northampton
Phone	01332365676
Email	admin@pwsa.co.uk
Website	www.pwsa.co.uk

Activities

Objects: 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.

Activities: 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 Trustee's shall determine.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Disability
- **Who:** People With Disabilities

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Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£657,800	£507,975	£580,098	10
2024-03-31	£497,574	£501,101	-	-
2023-03-31	£383,383	£518,900	-	-
2022-03-31	£361,569	£364,343	-	-
2021-03-31	£547,574	£328,376	£572,091	8

Trustees

Name	Role	Appointed
Andrew Abbott		2022-11-26
Anne Good		2017-11-25
Danny Leslie		2017-11-25
Dr Anne Livesey		2017-11-25
Dr Evelien Francesca Gevers		2023-11-18
Fiona Swinhoe		2024-10-19
Jackie Gill		2025-10-18
Karen Potts		2020-11-28
Laura Pearson		2024-10-19
Rebecca Neish		2024-10-19
Rosa McKay Polaschek		2023-11-18
Susan Passmore		2023-11-18

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PRADER-WILLI SYNDROME ASSOCIATION UK

England & Wales - Charity number 1155846

Accounts

REGISTERED CHARITY NUMBER: 1155846

REPORT OF THE TRUSTEES AND

UNAUDITED FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2025

FOR

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

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

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

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FOR THE YEAR ENDED 31 MARCH 2025

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PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2025

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

OBJECTIVES AND ACTIVITIES

Objectives and aims

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

- The objects of PWSA UK (the Association) are to relieve the charitable needs of people with Prader-Willi Syndrome and their families and carers by the provision of services, advice and support as the Trustees shall determine.

- The vision of PWSA UK is to overcome the challenges of Prader-Willi Syndrome.

- The mission of PWSA UK is to ensure every member of the PWS community has access to high quality care, opportunity, and support, and to promote awareness, build knowledge and further research in order to overcome the challenges of PWS.

- The values of PWSA UK are to work with those affected by PWS with integrity, objectivity, accountability, openness, honesty, and clear leadership.

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

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

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

Charitable activities

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

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

ACHIEVEMENTS AND PERFORMANCE

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

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

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

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

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

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

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

The PWSA UK team supported families and professionals throughout the year with 1,160 people accessing our services which resulted in 2,755 actions (phone calls, letters, and meetings) to resolve the issues.
Our prime sources of requests for help were:
- Helpline 25%
- Email 60%
- Facebook: 6%
- Clinics/ Family Net: 1%
- Website: 8%

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

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

PWSA UK is committed to working with PWS residential care providers to improve standards of care and quality of life for adults with PWS. A forum of PWS providers has been established with opportunities to learn and network through online webinars and meetings. A Charter for Care Homes has been drafted and will be rolled out to encourage adoption of core standards. A provider list (PWS Care Home directory) is being developed and will include expanded information for parents and commissioners.
A survey of parents of adults in care home settings has been undertaken as well as planning for regular 'listening' meetings. PWSA UK has worked in an advisory capacity with several providers who are looking to set up new services in underserved parts of UK.

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

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

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

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

4. To develop and maintain regional reach.

PWSA UK is committed to supporting all people impacted by PWS and annually map our reach and engagement. There has been a 20% increase in the numbers of people engaging with PWSA UK across the UK and notably higher in Scotland and London.
Funding was secured to employ a part time PWS Specialist Support Worker in Northern Ireland. Work has started to reach PWS families in Northern Ireland and engaging with health, education and social care professionals.

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

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

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

PWSA UK continues to work in partnership with FPWR UK through the PWS Stronger Together initiative. Through this collaboration three webinars have been delivered to provide updates on PWS clinical trials.
PWSA UK continues to provide input into trials and studies as the patient voice as well as promoting opportunities for participation in clinical trials and research.

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

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

6. To sustain the charity.

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

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

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

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

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

Volunteering

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

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

Income Generation

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

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

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

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

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

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

FINANCIAL REVIEW

Principal funding sources

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

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

Investment policy and objectives

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

Reserves policy

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

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

Pension Commitments

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

FUTURE PLANS

Strategic Objectives for 2025-26

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

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

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

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

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

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

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

4. To develop and maintain regional reach.

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

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

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

6. To sustain the charity.

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

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

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

STRUCTURE, GOVERNANCE AND MANAGEMENT

Charity constitution

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

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

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

Organisational structure

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

A new recruitment process has been agreed by the Trustees to ensure that Trustees are selected based on required skills and experience. As part of the ongoing review of governance the previous working groups were closed and replaced by new sub-committees which better meet the needs of our operations:
- Finance and General Purposes Committee
- Medical Advisory and Research Committee
- Services, Information and Training Committee
- Fundraising and Communications Committee

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

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

Declaration of Interest and Internal Controls

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

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

Risk management

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

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

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

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2025

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number
England and Wales: 1155846 Scotland: SC053700

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

Royal Patron	HRH The Princess Michael of Kent
Patron	Prof Tony Holland CBE
Trustees	Lt Col Danny Leslie MBE (Chairman) Matthew Christensen (Treasurer) Andrew Abbott Catherine Carey (resigned 15 September 2024) Dr Robin Chung Dr Evelien Gevers Anne Good Dr Anne Livesey Ian Metcalf (stood down 19 October 2024 - end of maximum term of office) Rebecca Neish (appointed 19 October 2024) Susan Passmore Laura Pearson (appointed 19 October 2024) Rose Polaschek Karen Potts Stephanie Sokolowski (resigned 19 July 2024) Fiona Swinhoe (appointed 19 October 2024)
Chief Executive and Honorary Secretary	Jackie Lodge

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

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

Approved by order of the board of trustees on .....18/10/25..... and signed on its behalf by:

.....
D Leslie - Trustee

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

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

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

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

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

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

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

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

David Mellor

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

Date: 29/10/2025

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 MARCH 2025

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

The notes form part of these financial statements

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

BALANCE SHEET
31 MARCH 2025

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

The financial statements were approved by the Board of Trustees and authorised for issue on .....18/10/25..... and were signed on its behalf by:

.....
D Leslie - Trustee

.....
K Potts - Trustee

The notes form part of these financial statements

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

CASH FLOW STATEMENT
FOR THE YEAR ENDED 31 MARCH 2025

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

The notes form part of these financial statements

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

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

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

2. ANALYSIS OF CHANGES IN NET FUNDS

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

The notes form part of these financial statements

1. STATUTORY INFORMATION

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

2. ACCOUNTING POLICIES

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

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

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

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

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

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

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

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

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

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

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

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

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

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.

2. ACCOUNTING POLICIES - continued

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

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

3. DONATIONS AND LEGACIES

	2025	2024
	£	£
Donations	**349,236**	402,450
Legacies	**184,102**	-
	533,338	402,450

4. OTHER TRADING ACTIVITIES

	2025	2024
	£	£
Promotional sales	**5,519**	4,531

5. INVESTMENT INCOME

	2025	2024
	£	£
Deposit account interest	**16,737**	11,416

6. INCOME FROM CHARITABLE ACTIVITIES

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

7. RAISING FUNDS

Other trading activities

	2025	2024
	£	£
Fundraising expenditure	17,169	13,798

8. CHARITABLE ACTIVITIES COSTS

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

9. DIRECT COSTS OF CHARITABLE ACTIVITIES

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

10. SUPPORT COSTS

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

10. SUPPORT COSTS - continued

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

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

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

11. TRUSTEES' REMUNERATION AND BENEFITS

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

Trustees' expenses

	2025 £	2024 £
Trustees' expenses	501	1,197

Trustees' expenses relate to attendance at meeting costs.

12. STAFF COSTS

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

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

	2025	2024
Charitable activities	11	9
Management and administration	1	1
	12	10

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

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

13. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

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

14. TANGIBLE FIXED ASSETS

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

15. STOCKS

	2025 £	2024 £
Finished goods	**3,051**	4,186

16. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

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

17. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2025	2024
	£	£
Other creditors	7,332	9,022

18. MOVEMENT IN FUNDS

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

18. MOVEMENT IN FUNDS - continued

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

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

18. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

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

18. MOVEMENT IN FUNDS - continued

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

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

Designated Funds as at 31 March 2025
Research - funding for research projects
Research: Ageing in PWS - funding for a specific research project
Residential Care Project Manager - funding for all relevant costs in relation to residential care
Ageing Research - James Ellis - Funding for research into the ageing process and effects on those with PWS
Community Events -Harrington - Funding for all expenses in relation to the cost of organising and executing community events within the UK
OWL Focus Group - Harrington - Funding for all associated costs to enable the OFG members (adults with PWS) to take part in a focus group quarterly both face to face and virtually
Engagement and Comms Manager - Funding for the role of Engagement and Communications Manager and all associated costs to enable fulfilment of their role
Boss Training - Funding towards a project worker to deliver BOSS (Be our successful self) to adults with PWS
Radio 4 Appeal 2025 - Funding towards the cost of operating the helpline
Report into PWS Deaths - Research into premature deaths within the PWS community and why
Family Weekends - Crown Holdings - Funding towards all associated costs to enable the successful organization and execution of all Community Family weekend events

18. MOVEMENT IN FUNDS - continued

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

Restricted Funds as at 31 March 2025
OWL Group - support for meetings and awaydays
Familynet events - funding for family activities
Familynet Cheshire and Hertfordshire - funding for family activities
National Conference 2020 - outsourcing activities - funding for creche facilities
Familynet Essex - funding for family activities
CAF - funding for Support Team and online activities
Awards4 All - funding for diagnosis support
Better Breaks Scotland - for use in Scotland only, for community events/family weekends
Postcode Places - for a new post recruited in January 2024 - volunteer co-ordinator who is taking a lead in all things volunteer related
Northern Ireland - for work to be undertaken within Northern Ireland to reach the community there
TSG Foundation - this is towards a new diagnosis lead in the support teams salary
PWSA Funds - The Big Give Foundation - to develop a resource for the community on how best to control diet within PWS
The Whitehead Monckton Trust - towards any costs relating to the PWS Walkover community event taking part in Hastings in July 2024
D'Oyly Carter Charitable Trust - to be used against any costs against the Dorset Community weekend taking place in September 2024
Wales - Toyota - Funding towards community events within the Wales area only
Scotlands Events - Inchcape Foundation - Funding towards community events within Scotland only
Music Therapy - HKM Charity - Funding towards activities that involve music therapy/sensory activities for those with PWS
New Diagnosis Packs - The Hospital Saturday Fund - Funding towards sensory baskets and information packs for New Diagnosis babies and families
Walkover Events UK - Souter Charitable Trust - Funding towards Walkover community events and all associated costs (an outside activity involving a walk around a country park)
PWSST - Ageing Research - Funding towards Research into the Ageing Process and the effects on those with PWS

19. EMPLOYEE BENEFIT OBLIGATIONS

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

20. RELATED PARTY DISCLOSURES

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

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

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

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

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

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

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

PRADER-WILLI SYNDROME ASSOCIATION UK

England & Wales - Charity number 1155846

Accounts

REGISTERED CHARITY NUMBER: 1155846

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
Derby
Derbyshire
DE1 1TJ

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

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FOR THE YEAR ENDED 31 MARCH 2024

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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.

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.

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.

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.

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.

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.

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.

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
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 ....19/10/2024..... 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
Derby
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	6				
Charitable activities		**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	7				
Charitable activities		**437,468**	**49,835**	**487,303**	507,162
Total		**449,551**	**51,550**	**501,101**	518,900
NET INCOME/(EXPENDITURE)		**(30,319)**	**26,792**	**(3,527)**	(135,517)
Transfers between funds	17	**(5,242)**	**5,242**	**-**	-
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		**358,040**	**63,618**	**421,658**	445,636
		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		**363,057**	**63,618**	**426,675**	430,926
TOTAL ASSETS LESS CURRENT LIABILITIES		**366,655**	**63,618**	**430,273**	433,800
NET ASSETS		**366,655**	**63,618**	**430,273**	433,800
FUNDS	17				
Unrestricted funds				**366,655**	402,215
Restricted funds				**63,618**	31,585
TOTAL FUNDS				**430,273**	433,800

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

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.

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.

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
	402,450	298,683

4. OTHER TRADING ACTIVITIES

	2024	2023
	£	£
Promotional sales	4,531	5,217

5. INVESTMENT INCOME

	2024	2023
	£	£
Deposit account interest	11,416	1,619

6. INCOME FROM CHARITABLE ACTIVITIES

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

7. CHARITABLE ACTIVITIES COSTS

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

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
	479,210	497,868

9. SUPPORT COSTS

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

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**
	8,093	**9,294**

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	1,197	2,345

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	15,962	11,854
	406,353	342,905

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

	2024	2023
Charitable activities	9	8
Management and administration	1	1
	10	9

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	1,619	-	1,619
Total	311,578	71,805	383,383
EXPENDITURE ON			
Raising funds	9,805	1,933	11,738

12. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

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

13. TANGIBLE FIXED ASSETS

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

14. STOCKS

	2024	2023
	£	£
Finished goods	4,186	3,189

15. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

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

16. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Other creditors	9,022	22,662

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
	402,215	(30,318)	(5,242)	366,655
Restricted funds				
Research	2,195	(2,195)	-	-
O.W.L Group	3,760	(551)	-	3,209
Children in Need	10,000	(275)	-	9,725
Research - Philip Barnes & Co Ltd	88	(5,333)	5,245	-
Familynet Wales & Southwest	1,012	(1,012)	-	-
ICAP	2,924	(2,477)	-	447
Alpkit Foundation	-	5	-	5
Awards 4 All	8,478	(5,316)	-	3,162
Toyota East Midlands	1,292	(494)	(798)	-
Jeans 4 Genes	1,836	(1,836)	-	-
Better Breaks Scotland 2023	-	274	-	274
Toyota	-	(795)	795	-
Postcode Places	-	19,385	-	19,385
Northern Ireland	-	11,102	-	11,102
TSG Foundation	-	5,211	-	5,211
PWSA Funds - The Big Give Campaign	-	7,586	-	7,586
The Whitehead Monckton Trust	-	352	-	352
D'Oyly Carter Charitable Trust	-	3,160	-	3,160
	31,585	26,791	5,242	63,618
TOTAL FUNDS	433,800	(3,527)	-	430,273

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)

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	569,317	(135,517)	-	433,800

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

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

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.

PRADER-WILLI SYNDROME ASSOCIATION UK

England & Wales - Charity number 1155846

Accounts

REGISTERED CHARITY NUMBER: 1155846

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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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.

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.

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.

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.

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.

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 down16 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
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

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		**311,578**	**71,805**	**383,383**	361,569
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		**417,465**	**101,435**	**518,900**	364,343
NET INCOME/(EXPENDITURE)		**(105,887)**	**(29,630)**	**(135,517)**	(2,774)
Transfers between funds	17	**44**	**(44)**	**-**	-
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		**402,215**	**31,585**	**433,800**	569,317

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		**408,806**	**36,830**	**445,636**	539,329
		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		**399,341**	**31,585**	**430,926**	566,900
TOTAL ASSETS LESS CURRENT LIABILITIES		**402,215**	**31,585**	**433,800**	569,317
NET ASSETS		**402,215**	**31,585**	**433,800**	569,317
FUNDS	17				
Unrestricted funds				**402,215**	508,058
Restricted funds				**31,585**	61,259
TOTAL FUNDS				**433,800**	569,317

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

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.

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.

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
	298,683	304,784

4. OTHER TRADING ACTIVITIES

	2023	2022
	£	£
Promotional sales	**5,217**	7,394

5. INVESTMENT INCOME

	2023	2022
	£	£
Deposit account interest	**1,619**	46

6. INCOME FROM CHARITABLE ACTIVITIES

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

7. CHARITABLE ACTIVITIES COSTS

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

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
	497,868	334,236

9. SUPPORT COSTS

	Management	Human resources	Other	Governance costs	Totals
	£	£	£	£	£
Charitable activities	**2,345**	**477**	**2,050**	**4,422**	**9,294**

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**
	9,294	**13,385**

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	**2,345**	2,396

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	**11,854**	9,233
	342,905	265,155

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

	2023	2022
Charitable activities	**8**	7
Management and administration	**1**	1
	9	8

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	46	-	46
Total	265,841	95,728	361,569
EXPENDITURE ON			
Raising funds	11,725	4,997	16,722
Charitable activities			
Charitable activities	250,862	96,759	347,621
Total	262,587	101,756	364,343

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	2,366	(2,366)	-
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	508,058	61,259	569,317

13. TANGIBLE FIXED ASSETS

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

14. STOCKS

	2023 **£**	2022 £
Finished goods	**3,189**	3,382

15. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

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

16. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023	2022
	£	£
Trade creditors	-	90
Other creditors	22,662	15,531
	22,662	15,621

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	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	569,317	(135,517)	-	433,800

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)**

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

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	361,569	(364,343)	(2,774)

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

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.

PRADER-WILLI SYNDROME ASSOCIATION UK

England & Wales - Charity number 1155846

Accounts

REGISTERED CHARITY NUMBER: 1155846

REPORT OF THE TRUSTEES AND

FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2022

FOR

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

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FOR THE YEAR ENDED 31 MARCH 2022

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PRADER-WILLI SYNDROME ASSOCIATION UK CIO

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2022

The trustees present their report with the financial statements of the charity for the year ended 31 March 2022. 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.

Charitable objects

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 Association exists to 'Cure the challenges of Life with 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 meets 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.

The services are available to individuals, families and institutions who are affected by PWS, whether or not they are members of the Association. Some activities require a financial contribution to be made where funding is not available, but the cost is generally subsidized by the Association and charges are not levied to the degree that would disadvantage participation by anyone with a limited income.

We encourage membership of the Association to all those interested in our work or concerned with the syndrome and have a modest membership subscription for families and professionals, and free to all people over 18 with PWS.
We currently have 422 Subscribed Members and 312 Members with PWS.

ACHIEVEMENT AND PERFORMANCE

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.

This is done by providing a telephone helpline, email and Facebook support, a wide range of information resources, family days and weekends as well as providing training, organizing conferences and contributing to the PWS knowledge transfer process.

Communication with our membership via the helpline, emails, Facebook and meetings continues to be the principal focus of our staff team, who supported families and professionals with 1,030 issues which resulted in 2,311 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, to support newly diagnosed families. The number of people coming to us with issues is now returning to pre-pandemic levels, but the complexity of those issues is far higher and the time it takes to resolve is increasing considerably. Much of this is a result of the pandemic; issues that have not been able to be addressed during lockdown have only worsened and the effect that lockdown has had on the wellbeing of our PWS community.

Our prime sources of requests for help were:
Helpline: 43%
Email: 31%
Facebook: 14%
Clinics/Familynet: 2%
Website: 10%

There were 35 New Diagnoses reported to PWSA UK this year and a further 25 possible New Diagnoses.

Staff and volunteers have, in previous years, attended PWS Specialist Clinics offering support and advice to families at the Royal Alexandra Brighton, the Chelsea and Westminster London, the Hammersmith Hospital London, the Birmingham Children's Hospital, the Royal Stoke University Hospital Stoke on Trent, Queen Elizabeth University Hospital Glasgow and the Royal Hospital for Sick Children in Edinburgh. However, due to Covid-19, hospital appointments this financial year have mostly been delivered virtually and support from the Association has been through referrals by the clinics.

Our website continues to develop, and we have introduced a dedicated research page where we can post updates from existing research projects and promote opportunities for our community to take part in new studies. We have also developed a dedicated events page, providing a month-by-month view of the Association's events calendar, both in terms of our own activities and external events where supporters are raising funds for us. With restrictions being eased over the past year, an increase in activities and events has enabled us to take new photos of our community, which we have been using to update the images on our website. We have continued to review and, where appropriate, update information pages across the website to ensure they remain as accessible as possible to visitors.

We continue to interact with our members through our Facebook page, Twitter account and Instagram. In March 2022 we had 5,731 followers on Facebook, 1,446 Twitter followers and 962 followers on Instagram. Our closed Facebook Group for UK families is called PWSA UK Community Hub - Empowering Life with PWS and it has 651 members. We also host a closed group for siblings called PWSA UK - Sibs Hub which has 34 members.We are also members of a further 6 parent led Facebook pages and respond with advice, information and support wherever possible. Social Media continues to be an important means of communication for our families and the Association is expanding its communications through these platforms.

We constantly review and update all our information and publications, and our flagship resource, Your PWS Journey continues to provide 'Everything you need to know about Prader-Willi Syndrome' in one place. Information and online resources are constantly being updated and gaps in information identified and filled. In this financial year we have updated twenty different information documents to ensure that our information remains the most up to date possible.

Covid-19 restrictions meant that PWSA UK moved all training onto virtual platforms. As most Residential Care and Supported Living Providers were still self-isolating or being very cautious about mixing with other people, this has fitted with most of their needs. PWSA delivered 31 online training sessions in this financial year to 296 attendees.

The National Conference originally planned for November 2020 and postponed to November 2021 had to once again be postponed because of Covid-19 restrictions. We held another virtual conference on 6th and 7th November 2021 across zoom which attracted 390 attendees. Our first face to face National Conference since the pandemic will now be held on the 4th and 5th March 2023.

ACHIEVEMENT AND PERFORMANCE - continued

Research

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.

The Association worked closely with Soleno Therapeutics in the financial year 31.03.20 with their Phase 3 Destiny PWS study - DCCR Efficacy and Safety Trial in young children and adults with PWS, to the UK. PWSA UK continues to work closely with Soleno Therapeutics as they pursue regulatory approval for DCCR.

We are currently working with one further Pharmaceutical Company interested in bringing a trial to the UK which we hope will begin in the Autumn of 2022.

Organisational Development

Volunteering network

The Association has always relied upon the goodwill, knowledge and experience of its volunteers, many of whom make themselves available to speak to other members to offer peer support when needed. Volunteers are an extremely valuable resource to the Association and are supported by a clear volunteering infrastructure, each with a named member of staff who work with them. This enables the Association to work closely with volunteers providing a wider and more locally based range of services. We currently have 22 volunteers who run the Familynet project.

Familynet, our network of peer to-peer support groups throughout the UK provides local social events, meetings and peer support to the wider PWS community. This financial year, the pandemic meant that no face-to-face meetings were able to be held and all Familynet events were moved online.

This year we held 57 virtual meet ups, coffee and chats and Teddy Bears' picnics attended by 224 adults with PWS, 83 children with PWS and 453 parents of those with PWS - a total of 760 people. Face-to-face Familynet events resumed in the Summer of 2022, with safety always be our priority. Monthly virtual Adult Zooms have continued with great success.

Income Generation

PWSA UK is not only member-led but also depends on the fundraising efforts of its members for 80% of its funding. Without this, the Association would be unable to operate and continue to provide its vital services to the PWS community. This year, as a result of the pandemic, none of the usual fundraising events were able to go ahead and the Association relied on virtual events, donations, legacies and grants from trusts.

We are also very grateful to the Muriel Jones Foundation for a grant of £25,000, to the Masonic Charitable Foundation for £5,000 per year for three years, to the Ecclesiastical Movement for Good for £1,000 and to Children in Need for £10,000 per year for three years. 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 £361,569 (2021: £547,574) and incurred expenditures of £364,343 (2021: £328,376) resulting in a deficit on operating activities of £2,774 (2021: surplus £219,198).

Income levels for 2021/2022 are more the norm as the previous year was a record result due to the level of legacy bequests.

Core income decreased by 33.97% and core expenditure increased by 11.04% compared with 2020-21, the Association continues to monitor its overheads closely.

Total funds as at 31 March 2022 stood at £569,317 (2021: £572,091) of which £61,260 (2021: £69,654) relate to restricted funds.

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 offering our charitable services.

Principal funding sources

The core activities of the Association have been funded from our core income. The Association is heavily reliant upon the efforts of our membership and others associated with the Charity.

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.

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. Currently all reserves are 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 accumulate a general reserve as well as a designated reserve to support specific purposes over the coming years. The "designated" reserves currently stand at £227,180.

The Trustees have agreed that the unrestricted reserves should not fall below four months operating costs. The balance of the Association's general reserves is currently £280,878. General unrestricted reserves now stand at 12.8 months of unrestricted operating costs and reflects legacy income in 2020/2021, which was exceptionally high for the charity, and will stand us in good stead going forward to achieve our aims.

Pension Commitments

The Association has reviewed its commitments with regard to pension liability and has taken appropriate action as set out in the financial statements. The Trustees do not consider that the Association is currently at risk from unfunded pension commitments but will keep the situation under review. The Association reached their staging date for automatic enrolment in March 16 and as required enrolled all eligible staff into a qualifying pension scheme.

FUTURE PLANS

Strategic Objectives for 2022-2023

The Association's focus is on ensuring that it continues to support Members in the best way possible and set the Association's evolving priorities relative to its available resources.

The core strategic objectives of the Association are:

1. To achieve sustainable growth
2. To be the number one knowledge and information hub for PWS in the UK
3. To provide the best possible support to those living with PWS and their families and carers
4. To maintain regional reach through its volunteer groups
5. To be the voice for those affected by PWS
6. To support and promote research into the management and alleviation of PWS

Strategic Review

The Trustees intend to conduct a full review of the Association's Strategy early in 2023 that will build on the previous review, incorporate lessons from the pandemic and address the changing environment that our community and charities find themselves in.

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 constituted as a charity in 1981 and registered with the Charity Commissioners under Charity Number 284583 in May 1982. In February 2014, a new Charitable Incorporated Organisation (CIO) was formed and registered with the Charity Commissioners under Charity Number 1155846. The original Unincorporated Organization Charity Number 284583 was then merged with the new CIO and all assets and liabilities transferred to it. The original unincorporated organization, Charity Number 284583, was then closed and removed from the Charity Commissioner's register. The Charity is also known as PWSA UK and operates from its address at PO Box 8478, Derby, DE1 9HT.

STRUCTURE, GOVERNANCE AND MANAGEMENT - continued

Organisational structure

The Association is governed by a Board of Trustees consisting of not less than four members of the Association. These are elected for three years at the Annual General Meeting (AGM) and together with any co-opted members, are the Trustees of the Association. 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 to five times a year.

The Association remains "parent led". It invites expressions of interest from prospective Trustees who are then invited to become involved with a particular aspect of its work. There will be a discussion with the Chairman and the Chief Executive in order to identify their strengths and particular interest and are provided with a comprehensive induction pack. Following a period as a Candidate Trustee, the prospective Trustee will be considered for election at a subsequent AGM.

The Trustee Board operates a sub-committee structure of working groups in order to best use the diverse skills of its members; these working groups are:

- Adults Working Group
- Campaign 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 Trustees have adopted the Charity Commission's guidance 'Good Governance: A Code for the Voluntary and Community Sector' and will audit their performance against this standard at the AGM.

The day-to-day authority and management of the Association's activities are delegated to the Chief Executive who prepares Board Reports on progress made against targets within the Strategic Plan, the Annual Business Plan and the Risk Management Strategy.

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 organization'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 at modest thresholds of commitment and expenditure.

The Association has adopted a Declaration of Interest statement that invites Board meeting participants to declare a 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 that is maintained by the office in Derby.

Risk management

The Trustee Board ensures that the major risks which the Association is exposed to have been identified, reviewed and assessed in order for systems to be established to mitigate those risks and in order to achieve our charitable objects.

The Risk Management Strategy has been produced by the Chair of Trustees and the Board looking at the areas of Governance, Operational, Financial, Environmental and External, Law and Regulation and is overseen by the Board of Trustees.

These risks are reviewed annually by the trustees and the trustee board receives interim reports on the action being taken to mitigate the identified major risks at their regular Board Meetings.

In this way the Association manages uncertainty and mitigates risk against activities that threaten its short, medium and long-term survival on behalf of its membership.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2022

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number
1155846

Principal address
PO Box 8478
DERBY
DE1 9HT

Royal Patron	HRH The Princess Michael of Kent	
Patron	Prof Tony Holland BSc, MBBS, MRCP, Dipl Hum Clin Genet	FRCPsych, MPhil,
Trustees	Danny Leslie (Chairman)	
	Matthew Christensen (Treasurer)	
	Catherine Carey	re-appointed November 2021
	Flynn Castles	re-appointed November 2021
	Robin Chung	re-appointed November 2021
	Manuela Consito	resigned 18 September 2021
	Anne Good	
	Anne Livesey	
	Ian Metcalf	
	Karen Potts	
	Stefania Rosso	
	Stephanie Sokolowski	
Chief Executive and Honorary Secretary	Susan Passmore	

Auditors
Johnson Tidsall Limited
Chartered Accountants
& Statutory Auditor
81 Burton Road
Derby
Derbyshire
DE1 1TJ

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

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2022

STATEMENT OF TRUSTEES' RESPONSIBILITIES

The trustees are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales, the Charities Act 2011, Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that period. In preparing those financial statements, the trustees are required to

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the board of trustees on 26/11/2022 and signed on its behalf by:

.....
D Leslie - Trustee

REPORT OF THE INDEPENDENT AUDITORS TO THE TRUSTEES OF PRADER-WILLI SYNDROME ASSOCIATION UK CIO

Opinion

We have audited the financial statements of Prader-Willi Syndrome Association UK CIO (the 'charity') for the year ended 31 March 2022 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 March 2022 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements
We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

In identifying and assessing the risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, we considered the following:

-The nature and control environment of the charity

-Our discussions with management and governance including whether they had knowledge of any actual, suspected or alleged fraud

-The internal controls to mitigate the risks of fraud

As a result of these procedures, we identified the greatest potential for material fraud to be in the following areas:

-The timing of revenue recognition
-Unusual journal entries
-Management override

Audit response to risks identified

As a result of performing the above we identified the following as key audit matters related to the potential risk of material misstatement or fraud:

-The recognition of donations and legacies
-The evaluation of estimates in respect of legacies

We also considered any laws and regulations that were central to the operation of the charity including charity law and employment law.

The following procedures were undertaken in respect of the risks where we identified the potential for material misstatement:

- Income transaction test was performed to ensure the completeness of income. Post year end donations, legacies and fundraising were reviewed to ensure that income was recognised in the correct accounting period. We also tested a sample of income debtors to subsequent remittances.

- A sample of journal entries were tested for appropriateness and enquiries were made of management as to the procedures in place for posting journal entries. During our audit we considered any large, unusual or transactions outside the normal course of business which were highlighted as a result of our testing.

- We reviewed the minutes of trustees' meetings and controls put in place by the board of trustees including a review of their risk assessment.

- At the planning stage we discussed with management any laws and regulations which were central to the operation of the charity.

-The financial statements were reviewed alongside our disclosure checklists to identify any unusual or unexpected relationships or any areas of noncompliance. Discussions were held with management where it was considered additional disclosures were required.

- We remained alert to any indications of fraud, material misstatement or non-compliance with laws and regulations throughout the audit including those relating to the financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Johnson Tidsall Ltd

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

Date: 5/12/2022

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 MARCH 2022

	Notes	Unrestricted funds £	Restricted funds £	**2022 Total funds £**	2021 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	3	**209,056**	**95,728**	**304,784**	503,351
Charitable activities					
Charitable activities		**49,345**	**-**	**49,345**	38,537
Other trading activities	4	**7,394**	**-**	**7,394**	5,533
Investment income	5	**46**	**-**	**46**	116
Other income		**-**	**-**	**-**	37
Total		**265,841**	**95,728**	**361,569**	547,574
EXPENDITURE ON					
Raising funds	7	**11,725**	**4,997**	**16,722**	7,509
Charitable activities	8				
Charitable activities		**250,862**	**96,759**	**347,621**	320,867
Total		**262,587**	**101,756**	**364,343**	328,376
NET INCOME/(EXPENDITURE)		**3,254**	**(6,028)**	**(2,774)**	219,198
Transfers between funds	18	**2,366**	**(2,366)**	**-**	-
Net movement in funds		**5,620**	**(8,394)**	**(2,774)**	219,198
RECONCILIATION OF FUNDS					
Total funds brought forward		**502,437**	**69,654**	**572,091**	352,893
TOTAL FUNDS CARRIED FORWARD		**508,057**	**61,260**	**569,317**	572,091

The notes form part of these financial statements

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

BALANCE SHEET
31 MARCH 2022

	Notes	Unrestricted funds £	Restricted funds £	**2022 Total funds £**	2021 Total funds £
FIXED ASSETS					
Tangible assets	14	**2,417**	-	**2,417**	2,944
CURRENT ASSETS					
Stocks	15	**3,382**	-	**3,382**	3,250
Debtors	16	**39,810**	-	**39,810**	169,405
Cash at bank and in hand		**478,070**	**61,259**	**539,329**	409,398
		521,262	**61,259**	**582,521**	582,053
CREDITORS					
Amounts falling due within one year	17	**(15,621)**	-	**(15,621)**	(12,906)
NET CURRENT ASSETS		**505,641**	**61,259**	**566,900**	569,147
TOTAL ASSETS LESS CURRENT LIABILITIES		**508,058**	**61,259**	**569,317**	572,091
NET ASSETS		**508,058**	**61,259**	**569,317**	572,091
FUNDS	18				
Unrestricted funds				**508,058**	502,437
Restricted funds				**61,259**	69,654
TOTAL FUNDS				**569,317**	572,091

The financial statements were approved by the Board of Trustees and authorised for issue on 26/11/22 and were signed on its behalf by:

.....
D Leslie - Trustee

.....
M Christensen - Trustee

The notes form part of these financial statements

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

CASH FLOW STATEMENT
FOR THE YEAR ENDED 31 MARCH 2022

	Notes	2022 £	2021 £
Cash flows from operating activities			
Cash generated from operations	1	**130,823**	116,702
Net cash provided by operating activities		**130,823**	116,702
Cash flows from investing activities			
Purchase of tangible fixed assets		**(938)**	(2,660)
Interest received		**46**	116
Net cash used in investing activities		**(892)**	(2,544)
Change in cash and cash equivalents in the reporting period		**129,931**	114,158
Cash and cash equivalents at the beginning of the reporting period		**409,398**	295,240
Cash and cash equivalents at the end of the reporting period		**539,329**	409,398

The notes form part of these financial statements

NOTES TO THE CASH FLOW STATEMENT
FOR THE YEAR ENDED 31 MARCH 2022

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

	2022 £	2021 £
Net (expenditure)/income for the reporting period (as per the Statement of Financial Activities)	**(2,774)**	219,198
Adjustments for:		
Depreciation charges	**1,465**	3,592
Profit on disposal of fixed assets	**-**	(37)
Interest received	**(46)**	(116)
Increase in stocks	**(132)**	(1,399)
Decrease/(increase) in debtors	**129,595**	(106,321)
Increase in creditors	**2,715**	1,785
Net cash provided by operations	**130,823**	116,702

2. ANALYSIS OF CHANGES IN NET FUNDS

	At 1/4/21 £	Cash flow £	At 31/3/22 £
Net cash			
Cash at bank and in hand	**409,398**	**129,931**	**539,329**
	409,398	**129,931**	**539,329**
Total	**409,398**	**129,931**	**539,329**

The notes form part of these financial statements

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. The adverse effects of the Coronavirus in 2020/21 were mitigated by a large legacy bequest and actual results exceeded expectations in the year with a surplus on unrestricted funds which were carried forward into 2021/22 with funds designated to meet the costs of future projects. 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 £14,412.

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.

The charity receives government grants in respect of the Coronavirus Job Retention Scheme. Income from government are recognised at fair value when the charity has entitlement after any performance conditions have been met, it is probable that the income will be received and the amount can be measured reliably.

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.

2. ACCOUNTING POLICIES - continued

Debtors
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.

Hire purchase and leasing commitments
Rentals paid under operating leases are charged to the Statement of Financial Activities on a straight line basis over the period of the lease.

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.

2. ACCOUNTING POLICIES - continued

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 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

	2022	2021
	£	£
Donations	**290,372**	294,414
Legacies	**14,412**	172,070
Grants	**-**	36,867
	304,784	503,351

Grants received, included in the above, are as follows:

	2022	2021
	£	£
Coronavirus Job Retention Scheme	**-**	36,867

4. OTHER TRADING ACTIVITIES

	2022	2021
	£	£
Promotional sales	**7,394**	5,533

5. INVESTMENT INCOME

	2022	2021
	£	£
Deposit account interest	**46**	116

6. INCOME FROM CHARITABLE ACTIVITIES

	Activity	2022 £	2021 £
Conferences holidays & support	Charitable activities	**16,660**	8,895
Fundraising events	Charitable activities	**32,685**	29,642
		49,345	38,537

7. RAISING FUNDS

Other trading activities

	2022 £	2021 £
Fundraising expenditure	**16,722**	7,509

8. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 9) £	Support costs (see note 10) £	Totals £
Charitable activities	**334,236**	**13,385**	**347,621**

9. DIRECT COSTS OF CHARITABLE ACTIVITIES

	2022 £	2021 £
Staff costs	**265,155**	262,084
Other operating leases	**1,258**	6,046
Rates and water	**-**	179
Insurance	**1,211**	1,686
Light and heat	**-**	221
Telephone	**5,691**	7,268
Postage and stationery	**7,052**	5,105
Printing costs	**7,790**	3,442
AIM management costs	**386**	455
Bank charges	**282**	288
Events	**4,343**	4,552
Travel and accommodation	**7,024**	948
Family weekend	**1,796**	455
Staff training	**2,748**	687
IT costs	**10,703**	11,626
Office machine maintenance	**4,449**	3,431
Subscriptions	**3,850**	2,451
Research	**10,498**	348
	334,236	311,272

10. SUPPORT COSTS

	Management	Human resources	Other	Governance costs	Totals
	£	£	£	£	£
Charitable activities	**2,396**	**3,140**	**1,465**	**6,384**	**13,385**

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

	2022 Charitable activities	2021 Total activities
	£	£
Trustees' remuneration etc	**2,396**	**(117)**
Sundries	**3,140**	**108**
Depreciation of tangible fixed assets	**1,465**	**3,592**
Auditors' remuneration	**4,932**	**4,740**
Accountancy and legal fees	**1,452**	**1,272**
	13,385	**9,595**

11. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2022 nor for the year ended 31 March 2021.

Trustees' expenses

	2022	2021
	£	£
Trustees' expenses	**2,396**	(117)

12. STAFF COSTS

	2022	2021
	£	£
Wages and salaries	**236,463**	235,333
Social security costs	**19,459**	18,553
Other pension costs	**9,233**	8,198
	265,155	262,084

Wages and salaries includes redundancy pay of £nil (2021: £1,412).

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

	2022	2021
Charitable activities	**7**	7
Management and administration	**1**	1
	8	8

During the year one employee (2021: no 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 £63,945 (2021: £58,438).

13. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	368,606	134,745	503,351
Charitable activities			
Charitable activities	38,537	-	38,537
Other trading activities	5,533	-	5,533
Investment income	116	-	116
Other income	37	-	37
Total	412,829	134,745	547,574
EXPENDITURE ON			
Raising funds	7,273	236	7,509
Charitable activities			
Charitable activities	233,547	87,320	320,867
Total	240,820	87,556	328,376
NET INCOME	172,009	47,189	219,198
Transfers between funds	(162)	162	-
Net movement in funds	171,847	47,351	219,198
RECONCILIATION OF FUNDS			
Total funds brought forward	330,590	22,303	352,893
TOTAL FUNDS CARRIED FORWARD	502,437	69,654	572,091

14. TANGIBLE FIXED ASSETS

	Fixtures and fittings £
COST	
At 1 April 2021	**19,504**
Additions	**938**
At 31 March 2022	**20,442**
DEPRECIATION	
At 1 April 2021	**16,560**
Charge for year	**1,465**
At 31 March 2022	**18,025**
NET BOOK VALUE	
At 31 March 2022	**2,417**
At 31 March 2021	2,944

15. STOCKS

	2022	2021
	£	£
Finished goods	**3,382**	3,250

16. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022	2021
	£	£
Legacy debtors	**35,000**	166,070
Other debtors	**933**	1,107
Prepayments and accrued income	**3,877**	2,228
	39,810	169,405

17. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022	2021
	£	£
Trade creditors	**90**	92
Other creditors	**15,531**	12,814
	15,621	12,906

18. 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**

18. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	**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 Autos Limited	**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	**361,569**	**(364,343)**	**(2,774)**

18. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/4/20 £	Net movement in funds £	Transfers between funds £	At 31/3/21 £
Unrestricted funds				
General fund	146,287	188,662	61,616	396,565
Database Renewal fund	3,572	(3,572)	-	-
Relationships DVD	2,894	-	(2,894)	-
Britain & PWS	14,768	-	(14,768)	-
Research	46,236	-	(31,236)	15,000
Campaigning	22,500	-	(22,500)	-
National Care Pathway fund	5,000	-	(5,000)	-
Model for Supported Living	25,000	-	(25,000)	-
National Conference 2020	30,000	-	(30,000)	-
Communications Manager	34,333	(13,081)	69,620	90,872
	330,590	172,009	(162)	502,437
Restricted funds				
Research	2,239	-	-	2,239
O.W.L Group	4,649	(7)	-	4,642
Computer equipment	2,366	-	-	2,366
Children in Need	1,801	(1,201)	-	600
Familynet West Midlands	28	-	-	28
Scotland	187	-	(187)	-
Research - Philip Barnes & Co Ltd	1,500	1,500	-	3,000
Research Rokeby School	585	(270)	-	315
Familynet events	2,194	(116)	349	2,427
Familynet Wales & Southwest	2,478	-	-	2,478
Familynet Cheshire & Hertfordshire	1,000	-	-	1,000
National Conference 2020 - Outsourcing activities	2,000	-	-	2,000
National Conference 2020	1,276	(567)	-	709
Familynet Essex	-	1,500	-	1,500
Garfield Weston Foundation	-	4,462	-	4,462
CAF	-	1,300	-	1,300
ICAP	-	40,588	-	40,588
	22,303	47,189	162	69,654
TOTAL FUNDS	352,893	219,198	-	572,091

18. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	412,829	(224,167)	188,662
Database Renewal fund	-	(3,572)	(3,572)
Communications Manager	-	(13,081)	(13,081)
	412,829	(240,820)	172,009
Restricted funds			
O.W.L Group	-	(7)	(7)
Children in Need	12,992	(14,193)	(1,201)
Research - Philip Barnes & Co Ltd	1,500	-	1,500
Research Rokeby School	-	(270)	(270)
Familynet events	-	(116)	(116)
National Conference 2020	1	(568)	(567)
Lottery COVID-19 response	9,980	(9,980)	-
Familynet Essex	1,500	-	1,500
Barrat Developments PLC	1,000	(1,000)	-
Garfield Weston Foundation	20,000	(15,538)	4,462
Masonic Charitable Trust	5,000	(5,000)	-
Pears Contact a Family	9,329	(9,329)	-
CAF	30,443	(29,143)	1,300
ICAP	43,000	(2,412)	40,588
	134,745	(87,556)	47,189
TOTAL FUNDS	547,574	(328,376)	219,198

18. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined position is as follows:

	At 1/4/20 £	Net movement in funds £	Transfers between funds £	At 31/3/22 £
Unrestricted funds				
General fund	146,287	235,609	(101,018)	280,878
Database Renewal fund	3,572	(3,572)	-	-
Relationships DVD	2,894	-	(2,894)	-
Britain & PWS	14,768	-	(14,768)	-
Research	46,236	(10,044)	(16,236)	19,956
Campaigning	22,500	-	(22,500)	-
National Care Pathway fund	5,000	-	(5,000)	-
Model for Supported Living	25,000	-	(25,000)	-
National Conference 2020	30,000	-	(30,000)	-
Communications Manager	34,333	(46,729)	69,620	57,224
Research: Ageing in PWS	-	-	100,000	100,000
PWS Siblings project	-	-	50,000	50,000
	330,590	175,264	2,204	508,058
Restricted funds				
Research	2,239	(315)	-	1,924
O.W.L Group	4,649	(668)	-	3,981
Computer equipment	2,366	-	(2,366)	-
Children in Need	1,801	(1,778)	-	23
Familynet West Midlands	28	(28)	-	-
Scotland	187	-	(187)	-
Research - Philip Barnes & Co Ltd	1,500	2,861	-	4,361
Research Rokeby School	585	(270)	-	315
Familynet events	2,194	(1,776)	349	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	1,276	(567)	-	709
Familynet Essex	-	1,414	-	1,414
CAF	-	33,431	-	33,431
ICAP	-	7,320	-	7,320
St James's Place	-	2,500	-	2,500
	22,303	41,160	(2,204)	61,259
TOTAL FUNDS	352,893	216,424	-	569,317

18. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	678,670	(443,061)	235,609
Database Renewal fund	-	(3,572)	(3,572)
Research	-	(10,044)	(10,044)
Communications Manager	-	(46,729)	(46,729)
	678,670	(503,406)	175,264
Restricted funds			
Research	-	(315)	(315)
O.W.L Group	-	(668)	(668)
Children in Need	12,992	(14,770)	(1,778)
Familynet West Midlands	-	(28)	(28)
Research - Philip Barnes & Co Ltd	3,000	(139)	2,861
Research Rokeby School	-	(270)	(270)
Familynet events	-	(1,776)	(1,776)
Familynet Wales & Southwest	-	(540)	(540)
National Conference 2020 - Outsourcing activities	-	(424)	(424)
National Conference 2020	1	(568)	(567)
Lottery COVID-19 response	9,980	(9,980)	-
Familynet Essex	1,500	(86)	1,414
Barrat Developments PLC	1,000	(1,000)	-
Garfield Weston Foundation	20,000	(20,000)	-
Masonic Charitable Trust	10,000	(10,000)	-
Pears Contact a Family	9,329	(9,329)	-
CAF	88,704	(55,273)	33,431
ICAP	43,000	(35,680)	7,320
A Clark Autos Limited	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
	230,473	(189,313)	41,160
TOTAL FUNDS	909,143	(692,719)	216,424

Designated Funds as at 31 March 2022
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 2022
Research - Funding for research projects
O.W.L Group - support for meetings and awaydays
Computer equipment - to purchase computers for staff as required
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 & S West - funding for family activities
Familynet Cheshire & Hertfordshire - funding for family activities
National Conference 2020 - outsourcing activities - funding for creche facilities
National Conference 2020 - funding for speakers

18. MOVEMENT IN FUNDS - continued

Restricted Funds as at 31 March 2022 - continued
Familynet Essex - funding for family activities
Garfield Weston Foundation - funding for a member of the Support Team and online activities
CAF - funding for Support Team and online activities
ICAP - funding for family activities
P Sowerby Foundation - funding to increase access
Postcode Lottery - funding to support marginalised groups and promote equality
St James's Place - funding for animation videos

Transfers between funds

During the year £165,000 was transferred to designated funds from general funds in respect of specific projects.

In addition, £2,366 was transferred from restricted funds to general unrestricted funds in respect of computer equipment, now fully depreciated, which was funded by a restricted grant.

19. EMPLOYEE BENEFIT OBLIGATIONS

The total contribution paid to Personal Pension Plans in the year for certain employees amounted to £9,233 (2021: £8,198).

20. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2022.

PRADER-WILLI SYNDROME ASSOCIATION UK

England & Wales - Charity number 1155846

Accounts

REGISTERED CHARITY NUMBER: 1155846

REPORT OF THE TRUSTEES AND

FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2021

FOR

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

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FOR THE YEAR ENDED 31 MARCH 2021

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REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2021

The trustees present their report with the financial statements of the charity for the year ended 31 March 2021. 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.

Charitable objects
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 Association exists to 'Cure the challenges of Life with 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 meets 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.

The services are available to individuals, families and institutions who are affected by PWS, whether or not they are members of the Association. Some activities require a financial contribution to be made where funding is not available, but the cost is generally subsidized by the Association and charges are not levied to the degree that would disadvantage participation by anyone with a limited income.

We encourage membership of the Association to all those interested in our work or concerned with the syndrome and have a modest membership subscription for families and professionals, and free to all people over 18 with PWS.
We currently have 467 Subscribed Members and 302 Members with PWS.

ACHIEVEMENT AND PERFORMANCE

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.

This is done by providing a telephone helpline, email and Facebook support, a wide range of information resources, family days and weekends as well as providing training, organizing conferences and contributing to the PWS knowledge transfer process.

Communication with our membership via the helpline, emails, Facebook and meetings continues to be the principal focus of our staff team, who supported families and professionals with 673 issues which resulted in 1,129 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, to support to newly diagnosed families. This figure is a substantial drop on previous years (2019/20 - 1,040) as many services were closed, those with PWS were mostly self-isolating, children being homeschooled, so issues involving EHCPs, schools, residential care and social services were in the main on hold.

Our prime sources of requests for help were:
Helpline: 39%
Email: 29%
Facebook: 28%
Clinics/Familynet: 2%
Website: 2%

There were 38 New Diagnoses reported to PWSA UK this year and a further 41 possible New Diagnoses.

Staff and volunteers have, in previous years, attended PWS Specialist Clinics offering support and advice to families at the Royal Alexandra Brighton, the Chelsea and Westminster London, the Hammersmith Hospital London, the Birmingham Children's Hospital, the Royal Stoke University Hospital Stoke on Trent, Queen Elizabeth University Hospital Glasgow and the Royal Hospital for Sick Children in Edinburgh. However, due to Covid-19, hospital appointments this financial year have mostly been delivered virtually and support from the Association has been through referrals by the clinics.

Our website continues to develop, and we have introduced a revolving carousel on the homepage so that we are able to flag important information. We have introduced a new 'I Have PWS' page for Adults with PWS written in easy read and containing information of particular interest to Adults with PWS. The New Diagnosis page has been updated following feedback from new parents and we plan to develop this further in the coming year. The Latest News section of the home Page is regularly updated, and the Corona Virus page has continued to carry the latest information relevant to our community. We are currently updating all the photos on the website, but this has been hampered this year by not being able to meet up with families at events. We hope that this will change in the coming year.

We continue to interact with our members through our Facebook page, Twitter account and Instagram. In March 2021 we had 5,677 followers on Facebook, 1,365 Twitter followers and 711 followers on Instagram. Our closed Facebook Group for UK families is called PWSA UK Community Hub - Empowering Life with PWS and it has 583 members. We also host a closed group for siblings called PWSA UK - Sibs Hub which has 30 members.
We are also members of a further 6 parent led Facebook pages and respond with advice, information and support wherever possible. Social Media continues to be an important means of communication for our families and the Association is expanding its communications through these platforms.

We constantly review and update all our information and publications, and our flagship resource, Your PWS Journey continues to provide 'Everything you need to know about Prader-Willi Syndrome' in one place. Information and online resources are constantly being updated and gaps in information identified and filled. In this financial year we have updated the Residential Care Providers List, The Future Pack, the EHCP Information and Guidance Pack, the Information for GPs, Information for Hospitals and the New Diagnosis Pack.

Covid-19 restrictions meant that PWSA UK moved all training onto virtual platforms. However, as most Residential Care and Supported Living Providers were required to self-isolate their clients and most schools were remote teaching for much of the year, training was not most settings' priority. As a result, PWSA delivered 6 training sessions in this financial year to 52 attendees.

The National Conference planned for November 2020 at The Hayes in Derbyshire had to become a Virtual Conference because of Covid-19 restrictions. The conference was held on 7th November 2020 across zoom and we were delighted that it attracted 396 attendees.

ACHIEVEMENT AND PERFORMANCE - continued

Research

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.

The Association worked closely with Soleno Therapeutics in the financial year 31.03.20 with their Phase 3 Destiny PWS study - DCCR Efficacy and Safety Trial in young children and adults with PWS, to the UK. PWSA UK continues to work closely with Soleno Therapeutics as they pursue regulatory approval for DCCR.

We are currently working with two further Pharmaceutical Companies interested in bringing trials to the UK.

Organisational Development

Volunteering network

The Association has always relied upon the goodwill, knowledge and experience of its volunteers, many of whom make themselves available to speak to other members to offer peer support when needed. Volunteers are an extremely valuable resource to the Association and are supported by a clear volunteering infrastructure, each with a named member of staff who work with them. This enables the Association to work closely with volunteers providing a wider and more locally based range of services. We currently have 22 volunteers who run the Familynet project.

Familynet, our network of peer to-peer support groups throughout the UK provides local social events, meetings and peer support to the wider PWS community. This year, the pandemic meant that no face-to-face meetings were able to be held and all Familynet events were moved online.

This year we held 52 virtual meet ups, coffee and chats and Teddy Bears' picnics attended by 200 adults with PWS, 150 children with PWS and 476 parents of those with PWS - a total of 826 people. Whilst we plan to resume face-to-face Familynet events in the autumn, safety will always be our priority. Monthly virtual Teddy Bears' picnics and Adult Zooms will continue.

Income Generation

PWSA UK is not only member-led but also depends on the fundraising efforts of its members for 80% of its funding. Without this, the Association would be unable to operate and continue to provide its vital services to the PWS community. This year, as a result of the pandemic, none of the usual fundraising events were able to go ahead and the Association relied on virtual events, donations, legacies and grants from trusts. We were particularly fortunate to receive substantial legacies from the late Mrs Lilian Betts, and the late MH Nash.

We are also very grateful to the Muriel Jones Foundation for a grant of £25,000 and to the Michael Bishop Foundation for a grant of £50,000. These grants and legacies not only enable us to continue our work with our PWS community but enable us to plan 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 £547,574 (2020: £414,974) and incurred expenditures of £328,376 (2020: £404,526) resulting in a surplus on operating activities of £219,198 (2020: £10,488).

Core income increased by 31.95% and core expenditure decreased by 18.82% compared with 2019-20 and the Association continues to monitor its overheads closely.

Total funds as at 31 March 2021 stood at £572,091 (2020: £352,893) of which £69,655 (2020: £22,303) relate to restricted funds.

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 offering our charitable services.

Principal funding sources

The core activities of the Association have been funded from our core income. The Association is heavily reliant upon the efforts of our membership and others associated with the Charity.

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.

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. Currently all reserves are held in the bank deposit account. There are no investments in equities, gifts or bonds.

FINANCIAL REVIEW - continued

Reserves policy

It is the policy of the Association to accumulate a general reserve as well as a designated reserve to support specific purposes over the coming years. The "designated" reserves currently stand at £105,872.

The Trustees have agreed that the unrestricted reserves should not fall below four months operating costs.. The balance of the Association's general reserves is currently £396,565. General unrestricted reserves now stand at 19.8 months of unrestricted operating costs and reflects legacy income of £172,070 which is considered much higher than the norm. This level will stand us in good stead during the current difficulties due to the COVID-19 pandemic.

Pension Commitments

The Association has reviewed its commitments with regard to pension liability and has taken appropriate action as set out in the financial statements. The Trustees do not consider that the Association is currently at risk from unfunded pension commitments but will keep the situation under review. The Association reached their staging date for automatic enrolment in March 16 and as required enrolled all eligible staff into a qualifying pension scheme.

FUTURE PLANS

Strategic Objectives for 2021-2022

The Association's focus is on ensuring that it continues to support Members in the best way possible and set the Association's evolving priorities relative to its available resources.

The core strategic objectives of the Association are:

1. To achieve sustainable growth
2. To be the number one knowledge and information hub for PWS in the UK
3. To provide the best possible support to those living with PWS and their families and carers
4. To maintain regional reach through its volunteer groups
5. To be the voice for those affected by PWS
6. To support and promote research into the management and alleviation of PWS

COVID-19 Impact

Prior to the pandemic the Trustees had undertaken a full review of the Association's Strategic Intent, Plan and Objectives. Core objectives remained but there were changes in the strategic approach that were designed to help better deliver the objectives. This included a new Mission Statement and Statement of Strategic Intent that set the context from which the objectives were drawn and identified the long-term pathway. Our ability to deliver on this new pathway was severely curtailed by the pandemic and lessons derived in that period have now set us on a further review of our strategy. In the coming year, the Trustees will again review the strategic approach in order to have a plan that will be delivered from mid-2022 onwards. Until that point the in-place strategy remains extant and within that several exciting projects such as the impact of Prader-Willi Syndrome in the older age group and the impact of being a sibling of someone with Prader-Willi Syndrome have begun.

Prader-Willi Syndrome continues to be identified by the NHS as one of the conditions that sees those diagnosed with it at greater risk than the wider population and therefore much of our membership (those with PWS and direct family groups) have 'shielded' throughout and continue to take a higher level of precaution than the wider population in the march back to normality. This experience is part of steering our future approach and strategic review so we can best support the Prader-Willi community.

COVID-19 has had a direct impact on fund-raising and maintaining business as usual. However, the Association implemented strict saving measures and targeted its expenditure so that support could be maintained through the crises and into the future. This prudent financial management has seen us emerge in a better position than originally forecast and allows us to embark on projects such as those listed above and a new strategic approach.

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 constituted as a charity in 1981 and registered with the Charity Commissioners under Charity Number 284583 in May 1982. In February 2014, a new Charitable Incorporated Organisation (CIO) was formed and registered with the Charity Commissioners under Charity Number 1155846. The original Unincorporated Organization Charity Number 284583 was then merged with the new CIO and all assets and liabilities transferred to it. The original unincorporated organization, Charity Number 284583, was then closed and removed from the Charity Commissioner's register. The Charity is also known as PWSA UK and operates from its address at PO Box 8478, Derby, DE1 9HT.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Organisational structure

The Association is governed by a Board of Trustees consisting of not less than four members of the Association. These are elected for three years at the Annual General Meeting (AGM) and together with any co-opted members, are the Trustees of the Association. 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 to five times a year at its office in Derby or in London.

The Association remains "parent led". It invites expressions of interest from prospective Trustees who are then invited to become involved with a particular aspect of its work. There will be a discussion with the Chairman and the Chief Executive in order to identify their strengths and particular interest and are provided with a comprehensive induction pack. Following a period as a Candidate Trustee, the prospective Trustee will be considered for election at a subsequent AGM.

The Trustee Board operates a sub-committee structure of working groups in order to best use the diverse skills of its members; these working groups are:

- Adults Working Group
- Campaign 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 Trustees have adopted the Charity Commission's guidance 'Good Governance: A Code for the Voluntary and Community Sector' and will audit their performance against this standard at the AGM.

The day-to-day authority and management of the Association's activities are delegated to the Chief Executive who prepares Board Reports on progress made against targets within the Strategic Plan, the Annual Business Plan and the Risk Management Strategy.

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 organization'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 at modest thresholds of commitment and expenditure.

The Association has adopted a Declaration of Interest statement that invites Board meeting participants to declare a 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 that is maintained by the office in Derby.

Risk management

The Trustee Board ensures that the major risks which the Association is exposed to have been identified, reviewed and assessed in order for systems to be established to mitigate those risks and in order to achieve our charitable objects.

The Risk Management Strategy has been produced by the Chair of Trustees and the Board looking at the areas of Governance, Operational, Financial, Environmental and External, Law and Regulation and is overseen by the Board of Trustees.

These risks are reviewed annually by the trustees and the trustee board receives interim reports on the action being taken to mitigate the identified major risks at their regular Board Meetings.

In this way the Association manages uncertainty and mitigates risk against activities that threaten its short, medium and long-term survival on behalf of its membership.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2021

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number
1155846

Principal address
PO Box 8478
DERBY
DE1 9HT

Trustees
Mrs S Passmore CEO
M J Christensen Treasurer
D S A Leslie Chairman

Royal Patron	HRH The Princess Michael of Kent	
Patron	Prof Tony Holland BSc, MBBS, MRCP, Dipl Hum Clin Genet	FRCPsych, MPhil,
Trustees	Danny Leslie (Chairman)	
	Matthew Christensen (Treasurer)	
	Catherine Carey	
	Flynn Castles	
	Robin Chung	
	Manuela Consito	appointed 28.11.2020
	Anne Good	
	Anne Livesey	
	Ian Metcalf	
	Karen Potts	appointed 28.11.2020
	Stefania Rosso	appointed 28.11.2020
	Stephanie Sokolowski	
	Neil Walker	resigned 28.11.2020
Chief Executive and Honorary Secretary	Susan Passmore	

Auditors
Johnson Tidsall Limited
Chartered Accountants
& Statutory Auditor
81 Burton Road
Derby
Derbyshire
DE1 1TJ

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

Bankers
HSBC Bank plc
1 St Peter's Street
Derby
DE1 2AE

STATEMENT OF TRUSTEES' RESPONSIBILITIES

The trustees are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales, the Charities Act 2011, Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that period. In preparing those financial statements, the trustees are required to

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the board of trustees on 30/11/21 and signed on its behalf by:

.....
D Leslie - Trustee

Opinion
We have audited the financial statements of Prader-Willi Syndrome Association UK CIO (the 'charity') for the year ended 31 March 2021 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:
- give a true and fair view of the state of the charity's affairs as at 31 March 2021 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion
We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern
In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information
The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements, or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Matters on which we are required to report by exception
We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:
- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees
As explained more fully in the Statement of Trustees' Responsibilities, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements
We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

In identifying and assessing the risks of material misstatement in respect of irregularities, including fraud and non-compliance with laws and regulations, we considered the following:

-The nature and control environment of the charity

-Our discussions with management and governance including whether they had knowledge of any actual, suspected or alleged fraud

-The internal controls to mitigate the risks of fraud

As a result of these procedures, we identified the greatest potential for material fraud to be in the following areas:

-The timing of revenue recognition
-Unusual journal entries
-Management override

Audit response to risks identified

As a result of performing the above we identified the following as key audit matters related to the potential risk of material misstatement or fraud:

-The recognition of donations and legacies
-The evaluation of estimates in respect of legacies

We also considered any laws and regulations that were central to the operation of the charity including charity law and employment law.

The following procedures were undertaken in respect of the risks where we identified the potential for material misstatement:

- Income transaction test was performed to ensure the completeness of income. Post year end donations, legacies and fundraising were reviewed to ensure that income was recognised in the correct accounting period. We also tested a sample of income debtors to subsequent remittances.

- A sample of journal entries were tested for appropriateness and enquiries were made of management as to the procedures in place for posting journal entries. During our audit we considered any large, unusual or transactions outside the normal course of business which were highlighted as a result of our testing.

- We reviewed the minutes of trustees' meetings and controls put in place by the board of trustees including a review of their risk assessment.

- At the planning stage we discussed with management any laws and regulations which were central to the operation of the charity.

-The financial statements were reviewed alongside our disclosure checklists to identify any unusual or unexpected relationships or any areas of non-compliance. Discussions were held with management where it was considered additional disclosures were required.

- We remained alert to any indications of fraud, material misstatement or non-compliance with laws and regulations throughout the audit including those relating to the financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Johnson Tidsall Ltd

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

Date: 4 JANUARY 2022

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 MARCH 2021

	Notes	Unrestricted funds £	Restricted funds £	2021 Total funds £	2020 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	3	**368,606**	**134,745**	**503,351**	304,315
Charitable activities	6				
Charitable activities		**38,537**	**-**	**38,537**	103,909
Other trading activities	4	**5,533**	**-**	**5,533**	6,211
Investment income	5	**116**	**-**	**116**	539
Other income		**37**	**-**	**37**	-
Total		**412,829**	**134,745**	**547,574**	414,974
EXPENDITURE ON					
Raising funds	7	**7,273**	**236**	**7,509**	17,949
Charitable activities	8				
Charitable activities		**233,547**	**87,320**	**320,867**	386,577
Total		**240,820**	**87,556**	**328,376**	404,526
NET INCOME		**172,009**	**47,189**	**219,198**	10,448
Transfers between funds	18	**(162)**	**162**	**-**	-
Net movement in funds		**171,847**	**47,351**	**219,198**	10,448
RECONCILIATION OF FUNDS					
Total funds brought forward		**330,590**	**22,303**	**352,893**	342,445
TOTAL FUNDS CARRIED FORWARD		**502,437**	**69,654**	**572,091**	352,893

The notes form part of these financial statements

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

BALANCE SHEET
31 MARCH 2021

	Notes	Unrestricted funds £	Restricted funds £	2021 Total funds £	2020 Total funds £
FIXED ASSETS					
Tangible assets	14	**2,944**	**-**	**2,944**	3,839
CURRENT ASSETS					
Stocks	15	**3,250**	**-**	**3,250**	1,851
Debtors	16	**169,405**	**-**	**169,405**	63,084
Cash at bank and in hand		**339,744**	**69,654**	**409,398**	295,240
		512,399	**69,654**	**582,053**	360,175
CREDITORS					
Amounts falling due within one year	17	**(12,906)**	**-**	**(12,906)**	(11,121)
NET CURRENT ASSETS		**499,493**	**69,654**	**569,147**	349,054
TOTAL ASSETS LESS CURRENT LIABILITIES		**502,437**	**69,654**	**572,091**	352,893
NET ASSETS		**502,437**	**69,654**	**572,091**	352,893
FUNDS	18				
Unrestricted funds				**502,437**	330,590
Restricted funds				**69,654**	22,303
TOTAL FUNDS				**572,091**	352,893

The financial statements were approved by the Board of Trustees and authorised for issue on

20/11/21 and were signed on its behalf by:

D Leslie - Trustee

M Christensen - Trustee

The notes form part of these financial statements

PRADER-WILLI SYNDROME ASSOCIATION UK CIO

CASH FLOW STATEMENT
FOR THE YEAR ENDED 31 MARCH 2021

	Notes	2021 £	2020 £
Cash flows from operating activities			
Cash generated from operations	1	**116,702**	(40,790)
Net cash provided by/(used in) operating activities		**116,702**	(40,790)
Cash flows from investing activities			
Purchase of tangible fixed assets		**(2,660)**	(1,553)
Interest received		**116**	539
Net cash used in investing activities		**(2,544)**	(1,014)
Change in cash and cash equivalents in the reporting period		**114,158**	(41,804)
Cash and cash equivalents at the beginning of the reporting period		**295,240**	337,044
Cash and cash equivalents at the end of the reporting period		**409,398**	295,240

The notes form part of these financial statements

NOTES TO THE CASH FLOW STATEMENT
FOR THE YEAR ENDED 31 MARCH 2021

1. RECONCILIATION OF NET INCOME TO NET CASH FLOW FROM OPERATING ACTIVITIES

	2021	2020
	£	£
Net income for the reporting period (as per the Statement of Financial Activities)	**219,198**	10,448
Adjustments for:		
Depreciation charges	**3,592**	6,299
Profit on disposal of fixed assets	**(37)**	-
Interest received	**(116)**	(539)
Increase in stocks	**(1,399)**	(582)
Increase in debtors	**(106,321)**	(43,849)
Increase/(decrease) in creditors	**1,785**	(12,567)
Net cash provided by/(used in) operations	**116,702**	(40,790)

2. ANALYSIS OF CHANGES IN NET FUNDS

	At 1/4/20	Cash flow	At 31/3/21
	£	£	£
Net cash			
Cash at bank and in hand	**295,240**	**114,158**	**409,398**
	295,240	**114,158**	**409,398**
Total	**295,240**	**114,158**	**409,398**

The notes form part of these financial statements

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 and risk assessment. The adverse effects of the Coronavirus in 2020/21 have been evaluated by the trustees. Cash flow is monitored on a regular basis and the trustees established a "worst case scenario" at the beginning of the financial year to assess the viability of the charity. Actual results exceeded expectations in the year with a surplus on unrestricted funds due to legacies receivable as at 31 March 2021. 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 £172,070.

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.

The charity receives government grants in respect of the Coronavirus Job Retention Scheme. Income from government are recognised at fair value when the charity has entitlement after any performance conditions have been met, it is probable that the income will be received and the amount can be measured reliably.

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.

2. ACCOUNTING POLICIES - continued

Income
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.

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.

Hire purchase and leasing commitments
Rentals paid under operating leases are charged to the Statement of Financial Activities on a straight line basis over the period of the lease.

2. ACCOUNTING POLICIES - continued

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 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

	2021	2020
	£	£
Donations	**294,414**	294,315
Legacies	**172,070**	10,000
Grants	**36,867**	-
	503,351	304,315

Grants received, included in the above, are as follows:

	2021	2020
	£	£
Coronavirus Job Retention Scheme	**36,867**	-

4. OTHER TRADING ACTIVITIES

	2021	2020
	£	£
Promotional sales	**5,533**	6,211

5. INVESTMENT INCOME

	2021	2020
	£	£
Deposit account interest	**116**	539

6. INCOME FROM CHARITABLE ACTIVITIES

	Activity	2021 £	2020 £
Conferences holidays & support	Charitable activities	**8,895**	25,417
Fundraising events	Charitable activities	**29,642**	78,492
		38,537	103,909

7. RAISING FUNDS

Other trading activities

	2021 £	2020 £
Fundraising expenditure	**7,509**	17,949

8. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 9) £	Support costs (see note 10) £	Totals £
Charitable activities	**311,272**	**9,595**	**320,867**

9. DIRECT COSTS OF CHARITABLE ACTIVITIES

	2021 £	2020 £
Staff costs	**262,084**	274,557
Other operating leases	**6,046**	11,710
Rates and water	**179**	455
Insurance	**1,686**	1,543
Light and heat	**221**	1,784
Telephone	**7,268**	4,684
Postage and stationery	**5,105**	6,702
Printing costs	**3,442**	10,373
AIM management costs	**455**	858
Bank charges	**288**	1,112
Events	**4,552**	-
Travel and accommodation	**948**	13,233
Residential care	**-**	3,813
Family weekend	**455**	7,090
Staff training	**687**	2,244
IT costs	**11,626**	13,215
Office machine maintenance	**3,431**	5,343
Subscriptions	**2,451**	3,331
Cleaning	**-**	225
Research	**348**	7,348
	311,272	369,620

10. SUPPORT COSTS

	Management	Human resources	Other	Governance costs	Totals
	£	£	£	£	£
Charitable activities	**(117)**	**108**	**3,592**	**6,012**	**9,595**

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

	2021 Charitable activities	2020 Total activities
	£	£
Trustees' remuneration etc	**(117)**	**5,160**
Sundries	**108**	**398**
Depreciation of tangible fixed assets	**3,592**	**6,299**
Auditors' remuneration	**4,740**	**4,740**
Accountancy and legal fees	**1,272**	**360**
	9,595	**16,957**

11. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2021 nor for the year ended 31 March 2020.

Trustees' expenses

	2021	2020
	£	£
Trustees' expenses	**(117)**	5,160

12. STAFF COSTS

	2021	2020
	£	£
Wages and salaries	**235,333**	243,551
Social security costs	**18,553**	21,021
Other pension costs	**8,198**	9,985
	262,084	274,557

Wages and salaries includes redundancy pay of £1,412 (2020: £nil).

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

	2021	2020
Charitable activities	**7**	7
Management and administration	**1**	1
	8	8

No employees received emoluments in excess of £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 £58,438 (2020: £62,154).

13. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	265,088	39,227	304,315
Charitable activities			
Charitable activities	103,909	-	103,909
Other trading activities	6,211	-	6,211
Investment income	539	-	539
Total	375,747	39,227	414,974
EXPENDITURE ON			
Raising funds	17,949	-	17,949
Charitable activities			
Charitable activities	343,629	42,948	386,577
Total	361,578	42,948	404,526
NET INCOME/(EXPENDITURE)	14,169	(3,721)	10,448
Transfers between funds	1,400	(1,400)	-
Net movement in funds	15,569	(5,121)	10,448
RECONCILIATION OF FUNDS			
Total funds brought forward	315,021	27,424	342,445
TOTAL FUNDS CARRIED FORWARD	330,590	22,303	352,893

14. TANGIBLE FIXED ASSETS

	Fixtures and fittings £
COST	
At 1 April 2020	**38,397**
Additions	**2,660**
Disposals	**(21,553)**
At 31 March 2021	**19,504**
DEPRECIATION	
At 1 April 2020	**34,558**
Charge for year	**3,592**
Eliminated on disposal	**(21,590)**
At 31 March 2021	**16,560**
NET BOOK VALUE	
At 31 March 2021	**2,944**
At 31 March 2020	3,839

15. STOCKS

	2021 £	2020 £
Finished goods	**3,250**	1,851

16. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2021 £	2020 £
Trade debtors	**166,070**	50,000
Other debtors	**1,107**	779
Prepayments and accrued income	**2,228**	12,305
	169,405	63,084

17. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2021 £	2020 £
Trade creditors	**92**	215
Other creditors	**12,814**	10,906
	12,906	11,121

18. MOVEMENT IN FUNDS

	At 1/4/20 £	Net movement in funds £	Transfers between funds £	At 31/3/21 £
Unrestricted funds				
General fund	146,287	188,662	61,616	396,565
Database Renewal fund	3,572	(3,572)	-	-
Relationships DVD	2,894	-	(2,894)	-
Britain & PWS	14,768	-	(14,768)	-
Research	46,236	-	(31,236)	15,000
Campaigning	22,500	-	(22,500)	-
National Care Pathway fund	5,000	-	(5,000)	-
Model for Supported Living	25,000	-	(25,000)	-
National Conference 2020	30,000	-	(30,000)	-
Communications Manager	34,333	(13,081)	69,620	90,872
	330,590	172,009	(162)	502,437
Restricted funds				
Research	2,239	-	-	2,239
O.W.L Group	4,649	(7)	-	4,642
Computer equipment	2,366	-	-	2,366
Children in Need	1,801	(1,201)	-	600
Familynet West Midlands	28	-	-	28
Scotland	187	-	(187)	-
Research - Philip Barnes & Co Ltd	1,500	1,500	-	3,000
Research Rokeby School	585	(270)	-	315
Familynet events	2,194	(116)	349	2,427
Familynet Wales & Southwest	2,478	-	-	2,478
Familynet Cheshire & Hertfordshire	1,000	-	-	1,000
National Conference 2020 - Outsourcing activities	2,000	-	-	2,000
National Conference 2020	1,276	(567)	-	709
Familynet Essex	-	1,500	-	1,500
Garfield Weston Foundation	-	4,462	-	4,462
CAF	-	1,300	-	1,300
ICAP	-	40,588	-	40,588
	22,303	47,189	162	69,654
TOTAL FUNDS	352,893	219,198	-	572,091

18. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	**412,829**	**(224,167)**	**188,662**
Database Renewal fund	**-**	**(3,572)**	**(3,572)**
Communications Manager	**-**	**(13,081)**	**(13,081)**
	412,829	**(240,820)**	**172,009**
Restricted funds			
O.W.L Group	**-**	**(7)**	**(7)**
Children in Need	**12,992**	**(14,193)**	**(1,201)**
Research - Philip Barnes & Co Ltd	**1,500**	**-**	**1,500**
Research Rokeby School	**-**	**(270)**	**(270)**
Familynet events	**-**	**(116)**	**(116)**
National Conference 2020	**1**	**(568)**	**(567)**
Lottery COVID-19 response	**9,980**	**(9,980)**	**-**
Familynet Essex	**1,500**	**-**	**1,500**
Barrat Developments PLC	**1,000**	**(1,000)**	**-**
Garfield Weston Foundation	**20,000**	**(15,538)**	**4,462**
Masonic Charitable Trust	**5,000**	**(5,000)**	**-**
Pears Contact a Family	**9,329**	**(9,329)**	**-**
CAF	**30,443**	**(29,143)**	**1,300**
ICAP	**43,000**	**(2,412)**	**40,588**
	134,745	**(87,556)**	**47,189**
TOTAL FUNDS	**547,574**	**(328,376)**	**219,198**

18. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/4/19 £	Net movement in funds £	Transfers between funds £	At 31/3/20 £
Unrestricted funds				
General fund	124,703	20,184	1,400	146,287
Database Renewal fund	3,572	-	-	3,572
Relationships DVD	2,894	-	-	2,894
Britain & PWS	14,768	-	-	14,768
Research	46,584	(348)	-	46,236
Campaigning	22,500	-	-	22,500
National Care Pathway fund	5,000	-	-	5,000
Model for Supported Living	25,000	-	-	25,000
National Conference 2020	30,000	-	-	30,000
Communications Manager	40,000	(5,667)	-	34,333
	315,021	14,169	1,400	330,590
Restricted funds				
Research	2,239	-	-	2,239
O.W.L Group	3,916	733	-	4,649
Computer equipment	4,732	-	(2,366)	2,366
Children in Need	1,553	248	-	1,801
Hospital Saturday fund	1,550	(1,550)	-	-
Familynet Yorkshire	826	(826)	-	-
Familynet Oxfordshire	200	(200)	-	-
Familynet Cheshire & Lancashire	333	(333)	-	-
Familynet West Midlands	860	(832)	-	28
PWS Healthy Futures	182	(4,529)	4,347	-
Scotland	742	(555)	-	187
Research - Philip Barnes & Co Ltd	1,500	-	-	1,500
Research Rokeby School	7,585	(4,825)	(2,175)	585
Volunteer kit bags	1,206	-	(1,206)	-
Familynet events	-	2,194	-	2,194
Familynet Wales & Southwest	-	2,478	-	2,478
Familynet Cheshire & Hertfordshire	-	1,000	-	1,000
National Conference 2020 - Outsourcing activities	-	2,000	-	2,000
National Conference 2020	-	1,276	-	1,276
	27,424	(3,721)	(1,400)	22,303
TOTAL FUNDS	342,445	10,448	-	352,893

18. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	375,747	(355,563)	20,184
Research	-	(348)	(348)
Communications Manager	-	(5,667)	(5,667)
	375,747	(361,578)	14,169
Restricted funds			
O.W.L Group	2,000	(1,267)	733
Children in Need	10,000	(9,752)	248
Hospital Saturday fund	5	(1,555)	(1,550)
Familynet Yorkshire	-	(826)	(826)
Familynet Oxfordshire	-	(200)	(200)
Familynet Cheshire & Lancashire	-	(333)	(333)
Familynet West Midlands	1	(833)	(832)
PWS Healthy Futures	-	(4,529)	(4,529)
Scotland	-	(555)	(555)
Research Rokeby School	2,175	(7,000)	(4,825)
Familynet events	7,313	(5,119)	2,194
Family weekends - Sandy balls	500	(500)	-
Familynet Wales & Southwest	3,000	(522)	2,478
Familynet Cheshire & Hertfordshire	1,000	-	1,000
New diagnosis pack and launch	4,957	(4,957)	-
National Conference 2020 - Outsourcing activities	2,000	-	2,000
National Conference 2020	1,276	-	1,276
Support teams in South	5,000	(5,000)	-
	39,227	(42,948)	(3,721)
TOTAL FUNDS	414,974	(404,526)	10,448

18. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined position is as follows:

	At 1/4/19 £	Net movement in funds £	Transfers between funds £	At 31/3/21 £
Unrestricted funds				
General fund	124,703	208,846	63,016	396,565
Database Renewal fund	3,572	(3,572)	-	-
Relationships DVD	2,894	-	(2,894)	-
Britain & PWS	14,768	-	(14,768)	-
Research	46,584	(348)	(31,236)	15,000
Campaigning	22,500	-	(22,500)	-
National Care Pathway fund	5,000	-	(5,000)	-
Model for Supported Living	25,000	-	(25,000)	-
National Conference 2020	30,000	-	(30,000)	-
Communications Manager	40,000	(18,748)	69,620	90,872
	315,021	186,178	1,238	502,437
Restricted funds				
Research	2,239	-	-	2,239
O.W.L Group	3,916	726	-	4,642
Computer equipment	4,732	-	(2,366)	2,366
Children in Need	1,553	(953)	-	600
Hospital Saturday fund	1,550	(1,550)	-	-
Familynet Yorkshire	826	(826)	-	-
Familynet Oxfordshire	200	(200)	-	-
Familynet Cheshire & Lancashire	333	(333)	-	-
Familynet West Midlands	860	(832)	-	28
PWS Healthy Futures	182	(4,529)	4,347	-
Scotland	742	(555)	(187)	-
Research - Philip Barnes & Co Ltd	1,500	1,500	-	3,000
Research Rokeby School	7,585	(5,095)	(2,175)	315
Volunteer kit bags	1,206	-	(1,206)	-
Familynet events	-	2,078	349	2,427
Familynet Wales & Southwest	-	2,478	-	2,478
Familynet Cheshire & Hertfordshire	-	1,000	-	1,000
National Conference 2020 - Outsourcing activities	-	2,000	-	2,000
National Conference 2020	-	709	-	709
Familynet Essex	-	1,500	-	1,500
Garfield Weston Foundation	-	4,462	-	4,462
CAF	-	1,300	-	1,300
ICAP	-	40,588	-	40,588
	27,424	43,468	(1,238)	69,654
TOTAL FUNDS	342,445	229,646	-	572,091

18. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	788,576	(579,730)	208,846
Database Renewal fund	-	(3,572)	(3,572)
Research	-	(348)	(348)
Communications Manager	-	(18,748)	(18,748)
	788,576	(602,398)	186,178
Restricted funds			
O.W.L Group	2,000	(1,274)	726
Children in Need	22,992	(23,945)	(953)
Hospital Saturday fund	5	(1,555)	(1,550)
Familynet Yorkshire	-	(826)	(826)
Familynet Oxfordshire	-	(200)	(200)
Familynet Cheshire & Lancashire	-	(333)	(333)
Familynet West Midlands	1	(833)	(832)
PWS Healthy Futures	-	(4,529)	(4,529)
Scotland	-	(555)	(555)
Research - Philip Barnes & Co Ltd	1,500	-	1,500
Research Rokeby School	2,175	(7,270)	(5,095)
Familynet events	7,313	(5,235)	2,078
Family weekends - Sandy balls	500	(500)	-
Familynet Wales & Southwest	3,000	(522)	2,478
Familynet Cheshire & Hertfordshire	1,000	-	1,000
New diagnosis pack and launch	4,957	(4,957)	-
National Conference 2020 - Outsourcing activities	2,000	-	2,000
National Conference 2020	1,277	(568)	709
Support teams in South	5,000	(5,000)	-
Lottery COVID-19 response	9,980	(9,980)	-
Familynet Essex	1,500	-	1,500
Barrat Developments PLC	1,000	(1,000)	-
Garfield Weston Foundation	20,000	(15,538)	4,462
Masonic Charitable Trust	5,000	(5,000)	-
Pears Contact a Family	9,329	(9,329)	-
CAF	30,443	(29,143)	1,300
ICAP	43,000	(2,412)	40,588
	173,972	(130,504)	43,468
TOTAL FUNDS	962,548	(732,902)	229,646

Designated Funds as at 31 March 2021
Research - funding for research projects
Communications Manager - 3 year funding for a Communications manager post.

Restricted Funds as at 31 March 2021
Research - Funding for research projects
OWL Group - support for meetings and awaydays
Computer equipment - to purchase computers for staff as required
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

18. MOVEMENT IN FUNDS - continued

National Conference 2020 - outsourcing activities - funding for creche facilities
National Conference 2020 - funding for speakers
Familynet Essex - funding for family activities
Garfield Weston Foundation - funding for a member of the Support Team and online activities
CAF - funding for Support Team and online activities
ICAP - funding for family activities

Transfers between funds

Due to the global pandemic, the trustees transferred most of the designated funds back to general funds based on a worst case scenario budget.

19. EMPLOYEE BENEFIT OBLIGATIONS

The total contribution paid to Personal Pension Plans in the year for certain employees amounted to £8,198 (2020: £9,985).

20. OTHER FINANCIAL COMMITMENTS

As at 31 March 2021 the charity had financial commitments totalling £nil (2020: £5,100) relating to rents.

21. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2021.