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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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**UNAUDITED**

**TRUSTEES' REPORT AND FINANCIAL STATEMENTS**

**FOR THE YEAR ENDED 31 DECEMBER 2024**

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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**REFERENCE AND ADMINISTRATIVE DETAILS OF THE CIO, ITS TRUSTEES AND ADVISERS  
FOR THE YEAR ENDED 31 DECEMBER 2024**

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<b>Trustees</b>	Tony Holland, President and Chair François Besnier, Vice President Scott Arant Karin Clarke Gaby Erazo Lynn Garrick Nathalie Kayadjanian Svetlana Labun Tunde Liplin Craig Moore Kate Woodcock Lantz Yap
<b>Charity (CIO) registered number</b>	1182873
<b>Principal office</b>	Salisbury House Station Road Cambridge CB1 2LA
<b>Independent Examiner</b>	M Hewett FCA DChA Peters Elworthy & Moore Chartered Accountants Salisbury House Station Road Cambridge CB1 2LA
<b>Bankers</b>	HSBC Bank Plc 63-64 St Andrews Street Cambridge CB2 3BZ
<b>CEO</b>	Margaret Walker - appointed January 2025 Marguerite Hughes - resigned February 2025

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## INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

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### TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2024

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The Trustees present their annual report together with the financial statements of the CIO for the year 1 January 2024 to 31 December 2024. The Trustees confirm that the annual report and financial statements of the CIO comply with the current statutory requirements, the requirements of the CIO's governing document and the provisions of the Statement of Recommended Practice (SORP) applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (second edition of the Charities SORP (FRS102) October 2019, effective 1 January 2019).

#### OBJECTIVES, ACTIVITIES AND MAIN ACHIEVEMENTS

##### a. Policies, Values and objectives

IPWSO works to improve the quality of life for all people with Prader Willi syndrome (PWS) and their families worldwide. We provide information and support to caregivers, health professionals and families. We encourage national PWS associations to exchange and share their projects and experiences. We fund free testing for diagnosis in countries where it is not available.

##### Values

1. **Global Solidarity.** We are committed to working for a more equal world where all people with PWS can achieve their full potential regardless of their economic, geographic or family circumstances.
2. **Commitment to Science.** We believe that people with PWS and their families deserve clinical care, treatment recommendations, services and support that are based on rigorous empirical research and we will promote scientific reasoning throughout our organisation.
3. **Collaboration.** Premised on a belief that we can all learn from each other and benefit from each other's work, we are committed to fostering new relationships, willingly supporting others, and working cooperatively with diverse stakeholders in pursuit of common goals.
4. **Respect for all.** We are committed to equality for all people regardless of their sex, sexual orientation or gender reassignment, their race, colour or religion, their disability, marriage status or age.

The objectives of the CIO are, for the public benefit:

1. **Building Communities.** To support the growth of new and existing PWS associations and unite the global PWS community for the benefit of all its members.
2. **Equal Opportunities.** To strive for a world where people with PWS have equal opportunities to their peers, and all people with PWS, and their families, have access to current, evidence-based knowledge, treatments, services and support.
3. **Research for all.** To disseminate research findings in ways that make current knowledge accessible to all and foster research that reflects the diverse needs of people with PWS and their families around the world.
4. **Funding to meet needs.** To attract adequate and sustainable IPWSO funding to enable us to better support people with PWS and their families, in particular those most in need.

The Vision of the CIO is:

A world where people with PWS and their families receive the services and support they need to fulfil their potential and achieve their goals.

The Mission of the CIO is:

To unite the global PWS community to collectively find solutions to the challenges of the syndrome and to support and advocate for people with PWS and their families, PWS associations, and professionals who work

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## INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

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### TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

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with people with PWS.

In setting objectives and planning for activities, the Trustees have given due consideration to general guidance published by the Charity Commission relating to public benefit, including the guidance 'Public benefit: running a charity (PB2)'.

#### **b. Activities undertaken to achieve objectives**

##### **Building Communities:**

- IPWSO fostered the growth of existing PWS associations by funding a variety of small projects including camps for people with PWS in Portugal, the development of a website by the PWS Association in Costa Rica and providing travel funds and support for expert speakers at PWS in-person and online conferences and meetings.
- Our Famcare Board held meetings to facilitate different time zones to bring families and carers together in a safe environment to discuss aspects of PWS and to develop appropriate guidance materials.
- We held information and consultation meetings on the Foundation for Prader Willi Research's Global PWS Registry and on "*Telling the Story of PWS*". These activities are designed to share information, explore new initiatives, encourage collaboration and gain a better understanding of the needs of the PWS community globally.
- Our Professional Providers and Caregivers Board (PPCB) launched a Caregivers Forum, the aim of which is to provide a virtual space for professional PWS caregivers worldwide to connect and collaborate.
- PPCB also held their 6<sup>th</sup> International PWS Caregivers' Conference in Berlin in May 2024.
- In 2024 IPWSO was a member of, or formally affiliated with, the following international organisations: European Medicines Agency, European Society of Endocrinology (ESE), EURORDIS, Global Genes, Healthcare Information for All (HIFA), International Alliance of Patients' Organizations (IAPO), International Collaboration on Rare Diseases and Orphan Drugs (ICORD), National Organization for Rare Disorders (NORD), Prader-Willi Syndrome Clinical Trial Consortium (PWS-CTC), and Rare Diseases International (RDI).

##### **Equal Opportunities:**

- The IPWSO Advice Service responded to over 100 enquiries from 40 countries.
- For the 22<sup>nd</sup> consecutive year we offered free diagnostic testing for PWS to families unable to access or afford testing in their own countries.
- A new publication entitled "People with Prader-Willi syndrome can avoid obesity" was created and translated into Arabic and French. We provided funding for the translation of key documents into Arabic and Spanish for PWS Associations in Egypt and Brazil.
- Grants were provided to help support conferences and meetings in Bulgaria, China, Mexico and New Zealand and input from IPWSO's experts was presented in-person and online.
- Travel Fellowships were provided for 5 medical professionals to attend the 15<sup>th</sup> Congress of the African Society for Paediatric and Adolescent Endocrinology (ASPAE) in Algiers, Algeria, and for delegate attendance at the 6<sup>th</sup> PWS Professional Providers and Caregivers Conference in Berlin. These grants were made available to people from underserved countries, such as Vietnam and Colombia who would not otherwise be able to attend.
- Our online library of educational resources continues to grow and the contents are made freely available and translated into numerous languages. This year we produced several short videos arising from the 6<sup>th</sup> International PWS Caregivers' Conference in Berlin on topics including ageing, what it is like to live with PWS, and friends, partnerships and sexuality.
- IPWSO hosted information tables at scientific conferences including the 15<sup>th</sup> Congress of the African Society of Paediatric and Adolescent Endocrinology (ASPAE 2024) in Algiers, Algeria (7-8 March 2024), the International Child Neurology Conference, Cape Town, South Africa (6 - 10 May 2024), the APPES-ISPAE Joint Meeting in Yashobhoomi, New Delhi, India (2-5 October 2024) and the European Society of Paediatric Endocrinology in Liverpool, UK (16-18 November 2024).

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## INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

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### TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

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#### Research for all:

- Our Research and Clinical Trials Committee held two Online Meetings. In September we held a *Clinical Trials Update Meeting*, bringing together the latest thinking, research findings and clinical trials from healthcare companies that are active in the PWS space and in November we focused on *Global Access to Therapies for People with Prader-Willi Syndrome: Understanding the Challenge and Seeking Solutions* and a presentation on IPWSO's preliminary results from a study on *Global Availability of Growth Hormone Treatment of PWS*.
- IPWSO presented at various conferences including ASPAE 2024 and ESPE 2024.
- IPWSO continued to provide an online resource of academic papers on clinical and scientific aspects of PWS.
- The Orphanet Journal of Rare Diseases published our study in February 2024 on *Residential Care - Body weight, behaviours of concern, and social contact in adults and adolescents with Prader-Willi syndrome in full-time care services: Findings from pooled international archival data*. Orphanet J Rare Dis. 2024 Feb 7;19(1):48.
- Work continues to interrogate data from IPWSO's study on *Global Availability of Growth Hormone Treatment for People with PWS*.
- Work continued on our study into *Improving mental health and well-being for people with PWS* which will be published in 2025.
- We helped fund research carried out by medical research professionals in Malaysia and India.

#### Funding to meet needs:

- In 2024 IPWSO held three Money Market Investment Accounts with HSBC with a total deposit of \$266,141 and benefiting from interest of \$11,637 at 31.12.24.
- We continue to aim to agree with funders a 15% allocation of grant income to project management costs.
- Our fundraising efforts were impacted by staffing difficulties in 2024 which prevented planned fundraising activities.
- Specific projects including educational outreach activities, support for small projects, meetings, conferences and workshops and travel fellowships. These were supported by funding from the healthcare industry and Friends of IPWSO (USA).

More information on IPWSO's work is available in the Annual Report.

## FINANCIAL REVIEW

### a. Going concern

After making appropriate enquiries, the Trustees have a reasonable expectation that the CIO has adequate resources to continue in operational existence for the foreseeable future. For this reason, they continue to adopt the going concern basis in preparing the financial statements. Further details regarding the adoption of the going concern basis can be found in the accounting policies.

### b. Reserves policy

As part of its ongoing financial monitoring, IPWSO has established an Investment Committee which in collaboration with IPWSO's Finance Committee, has recommended to the Trustees an appropriate level of financial reserves for 2024. IPWSO holds reserves to ensure it can continue operating when unexpected events occur, such as a sudden loss of an income stream or an unexpected cost. At 31 December 2024 a total of \$266,141 is invested in three money market accounts of which \$206,000 is retained for general reserves and \$60,141 in conference-specific reserves. At the year-end, reserves (representing unrestricted funds excluding any designated funds) amounted to \$294,146. The Trustees will look for opportunities to utilise excess reserves during 2025.

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## INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

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### TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2024

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#### **c. Results for the year**

Income received during the year totalled \$308,127 (2023: \$208,262), of which \$189,243 was restricted and \$118,884 was unrestricted. Restricted income came in the form of grants and donations from bodies within the healthcare industry, corporations and individuals. Expenditure totalled \$272,982 (2023: \$202,956), of which \$145,225 was spent from restricted funds.

There was a net surplus on restricted funds of \$78,577 which has increased brought forward funds to a total of \$153,519 (2023: \$74,942) to be carried forward. A deficit of \$43,432 on unrestricted funds, when deducted from opening funds, results in a total to be carried forward of \$294,146 (2023: \$337,578).

#### **STRUCTURE, GOVERNANCE AND MANAGEMENT**

##### **a. Constitution and governance**

International Prader-Willi Syndrome Organisation is a registered charity, number 1182873, and is constituted as a charitable incorporated organisation under a Governing document dated 9 April 2019.

##### **b. Methods of appointment or election of Trustees**

The management of the CIO is the responsibility of the Trustees who are elected and coopted under the terms of the Governing document.

##### **c. Organisational structure and decision making policies**

The charity's organisational structure was altered in 2022 and consists of a Board of Trustees and also Committees and Advisory Boards, each with its own terms of reference. The Board of Trustees decided to alter the regularity and format of meetings, now alternating monthly between Board Meetings and Consultation Meetings, the latter of which are open to volunteers and advisors and the objective of which is to review the charity's operations and strategy and to increase engagement and understanding of issues affecting the Charity. At other times all Trustees are kept informed of issues via email and they contribute to making key decisions. The extent to which Trustees' responsibilities for decisions affecting the development and operation of the charity are devolved day to day to the CEO, is set out in the CEO's contract of employment and terms of reference.

##### **d. Policies adopted for the induction and training of Trustees**

Potential and new Trustees are advised of the Charity's objectives, its activities and the public benefit requirement at the Trustees' Induction, and support is available to them from fellow Trustees. Other information regarding their duties as Trustees is available from the Charity Commission.

#### **PLANS FOR THE FUTURE**

IPWSO's plans for 2025 and onwards include preparation for the 12<sup>th</sup> International Prader-Willi Syndrome Conference: United in Hope (PWS 2025) to be held from 24-28 June 2025 at the Arizona Grand Resort and Spa in Phoenix, Arizona, USA, in partnership with Prader-Willi Syndrome Association, USA (PWSA | USA) and the Foundation for Prader-Willi Research (FPWR). IPWSO envisages that this unique collaboration will serve as a catalyst for the largest international PWS conference ever held. Marguerite Hughes, IPWSO's Chief Executive Officer, will be stepping down from her role for personal reasons with effect from 28 February 2025. She will be very much missed. Margaret Walker has been appointed as our new CEO and will take up the position from 1 January 2025. There will be a period of handover and Marguerite Hughes will continue to support IPWSO as a volunteer to assist with the delivery of PWS 2025. We will also recruit a new Fundraising and Communications Manager in 2025.

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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**TRUSTEES' REPORT (CONTINUED)  
FOR THE YEAR ENDED 31 DECEMBER 2024**

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**STATEMENT OF TRUSTEES' RESPONSIBILITIES**

The Trustees are responsible for preparing the Trustees' Report 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 & Wales 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 CIO and of its incoming resources and application of resources, including its income and expenditure, for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles of the Charities SORP (FRS 102);
- make judgments and accounting estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards (FRS 102) 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 CIO will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the CIO's transactions and disclose with reasonable accuracy at any time the financial position of the CIO and 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 Governing document. They are also responsible for safeguarding the assets of the CIO and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the members of the board of Trustees and signed on their behalf by:

*Craig Moore*

.....  
**Craig Moore**  
**Treasurer**

Date: 31 March 2025



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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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**INDEPENDENT EXAMINER'S REPORT  
FOR THE YEAR ENDED 31 DECEMBER 2024**

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**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION ('the CIO')**

I report to the charity Trustees on my examination of the accounts of the CIO for the year ended 31 December 2024.

**RESPONSIBILITIES AND BASIS OF REPORT**

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

I report in respect of my examination of the CIO's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

**INDEPENDENT EXAMINER'S STATEMENT**

Since the CIO's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I 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.

Your attention is drawn to the fact that the CIO has prepared the accounts in accordance with 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) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has been withdrawn.

I understand that this has been done in order for the accounts to provide a true and fair view in accordance with the Generally Accepted Accounting Practice effective for reporting periods beginning on or after 1 January 2015.

I have completed my examination. I confirm that no 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 CIO as required by section 130 of the 2011 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.

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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**INDEPENDENT EXAMINER'S REPORT (CONTINUED)  
FOR THE YEAR ENDED 31 DECEMBER 2024**

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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.

This report is made solely to the CIO's Trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. My work has been undertaken so that I might state to the CIO's Trustees those matters I am required to state to them in an Independent Examiner's Report and for no other purpose. To the fullest extent permitted by law, I do not accept or assume responsibility to anyone other than the CIO and the CIO's Trustees as a body, for my work or for this report.

Signed:

*Michael Hewett*

Dated: 02 April 2025

**M HEWETT FCA DCHA  
PETERS ELWORTHY & MOORE**

Chartered Accountants

Cambridge

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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**STATEMENT OF FINANCIAL ACTIVITIES  
FOR THE YEAR ENDED 31 DECEMBER 2024**

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	Note	Restricted funds 2024 \$	Unrestricted funds 2024 \$	Total funds 2024 \$	Total funds 2023 \$
<b>INCOME FROM:</b>					
Donations	2	183,816	56,928	240,744	183,017
Charitable activities	3	5,427	50,319	55,746	20,717
Investments	4	-	11,637	11,637	4,528
<b>TOTAL INCOME</b>		<b>189,243</b>	<b>118,884</b>	<b>308,127</b>	<b>208,262</b>
<b>EXPENDITURE ON:</b>					
Charitable activities	5	145,225	127,757	272,982	202,956
<b>TOTAL EXPENDITURE</b>		<b>145,225</b>	<b>127,757</b>	<b>272,982</b>	<b>202,956</b>
<b>NET INCOME/(EXPENDITURE)</b>		<b>44,018</b>	<b>(8,873)</b>	<b>35,145</b>	<b>5,306</b>
Transfers between funds	13	34,559	(34,559)	-	-
<b>NET MOVEMENT IN FUNDS</b>		<b>78,577</b>	<b>(43,432)</b>	<b>35,145</b>	<b>5,306</b>
<b>RECONCILIATION OF FUNDS:</b>					
Total funds brought forward		74,942	337,578	412,520	407,214
Net movement in funds		78,577	(43,432)	35,145	5,306
<b>TOTAL FUNDS CARRIED FORWARD</b>		<b>153,519</b>	<b>294,146</b>	<b>447,665</b>	<b>412,520</b>

The Statement of Financial Activities includes all gains and losses recognised in the year.

The notes on pages 11 to 24 form part of these financial statements.

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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**BALANCE SHEET  
AS AT 31 DECEMBER 2024**

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	Note	2024 \$	2023 \$
<b>CURRENT ASSETS</b>			
Debtors	10	4,000	17,776
Investments	11	266,141	207,057
Cash at bank and in hand		191,671	197,986
		461,812	422,819
Creditors: amounts falling due within one year	12	(14,147)	(10,299)
<b>NET CURRENT ASSETS</b>		<b>447,665</b>	412,520
<b>TOTAL NET ASSETS</b>		<b>447,665</b>	412,520
<b>CHARITY FUNDS</b>			
Restricted funds	13	153,519	74,942
Unrestricted funds	13	294,146	337,578
<b>TOTAL FUNDS</b>		<b>447,665</b>	412,520

The financial statements were approved and authorised for issue by the Trustees and signed on their behalf by:

*Craig Moore*

.....  
**Craig Moore**  
**Treasurer**

Date: 31 March 2025

The notes on pages 11 to 24 form part of these financial statements.

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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

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**1. ACCOUNTING POLICIES****1.1 BASIS OF PREPARATION OF FINANCIAL STATEMENTS**

The financial statements 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), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Charities Act 2011.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair' view. This departure has involved following the Charities SORP (FRS 102) published in October 2019 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

International Prader-Willi Syndrome Organisation meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy.

No significant estimates or judgements have been made in the course of preparing the financial statements.

**1.2 GOING CONCERN**

The trustees have reviewed the financial position of the CIO, and have a reasonable expectation that the CIO has adequate resources to continue in operational existence for the foreseeable future. Accordingly, the financial statements continue to be prepared on the going concern basis.

**1.3 FUND ACCOUNTING**

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the CIO and which have not been designated for other purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the CIO for particular purposes. The costs of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

Investment income, gains and losses are allocated to the appropriate fund.

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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

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**1. ACCOUNTING POLICIES (CONTINUED)****1.4 INCOME**

All income is recognised once the CIO has entitlement to the income, it is probable that the income will be received and the amount of income receivable can be measured reliably.

On receipt, donated professional services and facilities are recognised on the basis of the value of the gift to the CIO which is the amount it would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

Grants are included in the Statement of Financial Activities on a receivable basis. The balance of income received for specific purposes but not expended during the period is shown in the relevant funds on the Balance Sheet. Where income is received in advance of entitlement of receipt, its recognition is deferred and included in creditors as deferred income. Where entitlement occurs before income is received, the income is accrued.

Gifts in kind donated for distribution are included at valuation and recognised as income when they are distributed to the projects. Gifts donated for resale are included as income when they are sold.

Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation. Donations are recognised in the period in which they are received.

Membership fee income, billed on a calendar year basis, is recognised in the period to which it relates.

Conference registration fees are recognised after the conference has taken place. Fees received in advance are deferred.

Other income is recognised in the period in which it is receivable and to the extent the goods have been provided or on completion of the service.

**1.5 EXPENDITURE**

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, 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 classified by activity.

Expenditure on charitable activities is incurred on directly undertaking the activities which further the CIO's objectives, as well as any associated support costs. Support costs including governance costs are those costs incurred in support of expenditure on the objects of the Charity. Governance costs are those incurred in connection with administration of the Charity and compliance with constitutional and statutory requirements.

Grants payable are charged in the year when the offer is made except in those cases where the offer is conditional, such grants being recognised as expenditure when the conditions attaching are fulfilled. Grants offered subject to conditions which have not been met at the year end are noted as a commitment, but not accrued as expenditure.

All expenditure is inclusive of irrecoverable VAT.

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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

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**1. ACCOUNTING POLICIES (CONTINUED)****1.6 INTEREST RECEIVABLE**

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the CIO; this is normally upon notification of the interest paid or payable by the institution with whom the funds are deposited.

**1.7 FOREIGN CURRENCIES**

Monetary assets and liabilities denominated in foreign currencies are translated into dollars at rates of exchange ruling at the reporting date.

Transactions in foreign currencies are translated into dollars at the rate ruling on the date of the transaction.

Exchange gains and losses are recognised in the Statement of Financial Activities.

**1.8 DEBTORS**

Trade and other debtors are recognised at the settlement amount after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

**1.9 CASH AT BANK AND IN HAND**

Cash at bank and in hand includes cash and short-term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

**1.10 LIABILITIES AND PROVISIONS**

Liabilities are recognised when there is an obligation at the Balance Sheet date as a result of a past event, it is probable that a transfer of economic benefit will be required in settlement, and the amount of the settlement can be estimated reliably.

Liabilities are recognised at the amount that the CIO anticipates it will pay to settle the debt or the amount it has received as advanced payments for the goods or services it must provide.

**1.11 FINANCIAL INSTRUMENTS**

The CIO only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

**1.12 PENSIONS**

The CIO operates a defined contribution pension scheme and the pension charge represents the amounts payable by the CIO to the fund in respect of the year.

**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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

**2. INCOME FROM DONATIONS**

	<b>Restricted funds 2024 \$</b>	<b>Unrestricted funds 2024 \$</b>	<b>Total funds 2024 \$</b>	<b>Total funds 2023 \$</b>
Donations	44,479	56,928	<b>101,407</b>	96,369
Grants	139,337	-	<b>139,337</b>	86,648
<b>TOTAL 2024</b>	<b>183,816</b>	<b>56,928</b>	<b>240,744</b>	<b>183,017</b>
<b>TOTAL 2023</b>	<b>140,029</b>	<b>42,988</b>	<b>183,017</b>	

Included in donations is a \$6,405 gift in kind relating to legal advice.

**3. INCOME FROM CHARITABLE ACTIVITIES**

	<b>Restricted funds 2024 \$</b>	<b>Unrestricted funds 2024 \$</b>	<b>Total funds 2024 \$</b>	<b>Total funds 2023 \$</b>
Member subscriptions	-	9,728	<b>9,728</b>	10,252
Diagnostic testing	5,427	-	<b>5,427</b>	5,465
PWSA USA Association (ECHO project)	-	-	-	5,000
Conference registration fees	-	40,591	<b>40,591</b>	-
<b>TOTAL 2024</b>	<b>5,427</b>	<b>50,319</b>	<b>55,746</b>	<b>20,717</b>
<b>TOTAL 2023</b>	<b>5,465</b>	<b>15,252</b>	<b>20,717</b>	



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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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**NOTES TO THE FINANCIAL STATEMENTS  
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**4. INVESTMENT INCOME**

	<b>Unrestricted funds 2024 \$</b>	<b>Total funds 2024 \$</b>	<b>Total funds 2023 \$</b>
Money market interest	11,637	<b>11,637</b>	4,528
TOTAL 2023	4,528	4,528	

**5. ANALYSIS OF EXPENDITURE BY ACTIVITIES**

	<b>Activities undertaken directly 2024 \$</b>	<b>Grant funding of activities 2024 \$</b>	<b>Support costs 2024 \$</b>	<b>Total funds 2024 \$</b>	<b>Total funds 2023 \$</b>
Charitable expenditure	221,087	6,730	45,165	<b>272,982</b>	202,956
TOTAL 2023	173,973	7,899	21,084	202,956	

**ANALYSIS OF DIRECT COSTS**

	<b>Total funds 2024 \$</b>	<b>Total funds 2023 \$</b>
Staff costs	<b>113,635</b>	119,130
Conferences and events costs	<b>99,522</b>	44,174
Diagnostic testing	<b>4,729</b>	7,261
Website costs	<b>3,201</b>	2,332
Translations	-	1,076
	<b>221,087</b>	173,973

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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**NOTES TO THE FINANCIAL STATEMENTS  
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**5. ANALYSIS OF EXPENDITURE BY ACTIVITIES (CONTINUED)**

**ANALYSIS OF SUPPORT COSTS**

	<b>Total funds 2024 \$</b>	Total funds 2023 \$
Accountancy and bookkeeping fees	<b>10,676</b>	10,462
Foreign currency exchange	<b>12,028</b>	(7,821)
Advertising and marketing	<b>284</b>	200
Insurance	<b>3,709</b>	1,512
IT software and consumables	<b>2,420</b>	1,866
Bank charges	<b>1,076</b>	968
Miscellaneous expenses	<b>1,340</b>	1,163
Office running costs	<b>5,982</b>	4,949
Professional and consultancy fees	<b>7,650</b>	7,785
	<b>45,165</b>	21,084

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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

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**6. ANALYSIS OF GRANTS**

	<b>Grants to Institutions 2024 \$</b>	<b>Grants to Individuals 2024 \$</b>	<b>Total funds 2024 \$</b>	<b>Total funds 2023 \$</b>
Microgrants	5,147	1,583	<b>6,730</b>	7,899
TOTAL 2023	<u>6,437</u>	<u>1,462</u>	<u>7,899</u>	

The CIO has made the following material grants to institutions during the year:

<b>NAME OF INSTITUTION</b>	<b>2024 \$</b>	<b>2023 \$</b>
The SPINE Foundation	-	450
Magyar Prader-Willi Szindróma Egyesület	-	1,493
Aster CMI Hospital	-	1,500
PWS Thailand Association	-	1,500
Taylor's University Malaysia	-	1,494
University Kebangsaan Malaysia	<b>1,000</b>	-
Associação Brasileira da Síndrome de Prader-Willi	<b>1,162</b>	-
Associação SPW Portugal	<b>1,200</b>	-
ASOPRAWI (PWS Costa Rica)	<b>1,085</b>	-
Aster CMI Hospital	<b>700</b>	-
	<u><b>5,147</b></u>	<u>6,437</u>

**7. INDEPENDENT EXAMINER'S REMUNERATION**

	<b>2024 \$</b>	<b>2023 \$</b>
Fees payable to the CIO's independent examiner for the independent examination of the CIO's annual accounts	<b>1,969</b>	1,908
Fees payable to the CIO's independent examiner in respect of:		
Preparation of statutory financial statements	<b>2,809</b>	2,723
Bookkeeping services	<b>4,599</b>	4,483

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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**NOTES TO THE FINANCIAL STATEMENTS  
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**8. STAFF COSTS AND KEY MANAGEMENT PERSONNEL**

	<b>2024</b>	<b>2023</b>
	<b>\$</b>	<b>\$</b>
Wages and salaries	<b>106,690</b>	113,233
Social security costs	<b>3,502</b>	3,746
Contribution to defined contribution pension schemes	<b>3,443</b>	2,151
	<b>113,635</b>	119,130
	<b>113,635</b>	119,130

The average number of persons employed by the CIO during the year was as follows:

	<b>2024</b>	<b>2023</b>
	<b>No.</b>	<b>No.</b>
Staff	<b>4</b>	4
	<b>4</b>	4

No employee received remuneration amounting to more than \$60,000 in either year.

The charity considers its key management personnel to be the Trustees and the CEO, Marguerite Hughes. During the year, the CEO received remuneration (comprising gross salary, employer's national insurance and employer's pension contributions) totalling \$20,281 (2023: \$19,860).

**9. TRUSTEES' REMUNERATION AND EXPENSES**

During the year, no Trustees received any remuneration or other benefits (2023 - \$NIL).

During the year ended 31 December 2024, expenses totalling \$7,556 were reimbursed or paid directly to 6 Trustees (2023 - \$5,072 to 3 Trustees). These expenses related to travel, accommodation and subsistence.

**10. DEBTORS**

	<b>2024</b>	<b>2023</b>
	<b>\$</b>	<b>\$</b>
Trade debtors	<b>4,000</b>	17,776
	<b>4,000</b>	17,776

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FOR THE YEAR ENDED 31 DECEMBER 2024**

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**11. CURRENT ASSET INVESTMENTS**

	<b>2024</b>	<b>2023</b>
	<b>\$</b>	<b>\$</b>
Money market investments (maturing between 6 months and 1 year)	<b>266,141</b>	207,057
	<u><u>266,141</u></u>	<u><u>207,057</u></u>

**12. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	<b>2024</b>	<b>2023</b>
	<b>\$</b>	<b>\$</b>
Trade creditors	<b>2,052</b>	4,757
Other taxation and social security	<b>1,826</b>	296
Other creditors	<b>640</b>	453
Accruals and deferred income	<b>9,629</b>	4,793
	<u><u>14,147</u></u>	<u><u>10,299</u></u>

	<b>2024</b>	<b>2023</b>
	<b>\$</b>	<b>\$</b>
Deferred income at 1 January 2024	<b>163</b>	-
Resources deferred during the year	-	163
Amounts released from previous periods	<b>(163)</b>	-
	<u><u>-</u></u>	<u><u>163</u></u>

Deferred income represents 2024 membership fees received in advance.

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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

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**13. STATEMENT OF FUNDS**

**STATEMENT OF FUNDS - CURRENT YEAR**

	Balance at 1 January 2024 \$	Income \$	Expenditure \$	Transfers in/out \$	Balance at 31 December 2024 \$
<b>UNRESTRICTED FUNDS</b>					
General Funds	337,578	118,884	(127,757)	(34,559)	294,146
<b>RESTRICTED FUNDS</b>					
Attendance at educational conferences	17,500	42,837	(30,683)	10,000	39,654
Diagnostic testing	829	5,427	(5,330)	-	926
6th International Caregivers Conference - Berlin	12,001	19,647	(65,948)	34,300	-
Friends: translations	1,098	-	(4)	-	1,094
Friends: meetings and workshops	23,064	-	(16,300)	(6,764)	-
Friends: travel scholarship PCC (Berlin)	4,600	-	(3,561)	(1,039)	-
Friends 3 year grant	-	100,000	(9,377)	-	90,623
Friends: microgrants	11,050	-	(7,597)	(1,049)	2,404
Friends: filming PPC 2024 conference	4,800	-	-	(4,800)	-
Friends: travel and strategic fellowships for 12th International Conference	-	11,500	(4,410)	3,911	11,001
Translation and interpretation	-	5,000	15	-	5,015
IPWSO Caregivers' Forum	-	4,000	(2,000)	-	2,000
12th International Conference - other funding	-	832	(30)	-	802
	<u>74,942</u>	<u>189,243</u>	<u>(145,225)</u>	<u>34,559</u>	<u>153,519</u>
<b>TOTAL OF FUNDS</b>	<u><u>412,520</u></u>	<u><u>308,127</u></u>	<u><u>(272,982)</u></u>	<u><u>-</u></u>	<u><u>447,665</u></u>

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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

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**13. STATEMENT OF FUNDS (CONTINUED)**

**STATEMENT OF FUNDS - PRIOR YEAR**

	Balance at 1 January 2023 \$	Income \$	Expenditure \$	Transfers in/out \$	Balance at 31 December 2023 \$
<b>UNRESTRICTED FUNDS</b>					
General Funds	368,878	62,768	(116,277)	22,209	337,578
<b>RESTRICTED FUNDS</b>					
Advice line	-	1,347	(1,327)	(20)	-
Attendance at educational conferences	-	40,760	(15,830)	(7,430)	17,500
Diagnostic testing	6,079	5,465	(10,915)	200	829
6th International Caregivers Conference - Berlin	-	17,500	(502)	(4,997)	12,001
Consultancy funding	-	6,035	(6,049)	14	-
ECHO funding	-	11,000	(11,065)	65	-
European Congress of Endocrinology 2023	-	435	(435)	-	-
Friends: CRM System	2,253	-	-	(2,253)	-
Friends: translations	-	2,000	(915)	13	1,098
Friends: Pakistan conference	7,380	-	-	(7,380)	-
Friends: meetings and workshops	20,270	40,752	(28,628)	(9,330)	23,064
Friends: travel scholarship PCC (Berlin)	-	-	-	4,600	4,600
Friends: microgrants	-	20,200	(11,013)	1,863	11,050
Friends: filming PPC 2024 conference	-	-	-	4,800	4,800
Raising Awareness	2,354	-	-	(2,354)	-
	<u>38,336</u>	<u>145,494</u>	<u>(86,679)</u>	<u>(22,209)</u>	<u>74,942</u>
<b>TOTAL OF FUNDS</b>	<u><u>407,214</u></u>	<u><u>208,262</u></u>	<u><u>(202,956)</u></u>	<u><u>-</u></u>	<u><u>412,520</u></u>

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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

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**13. STATEMENT OF FUNDS (CONTINUED)**

IPWSO Advice Line – this fund represents monies raised from fundraising campaigns to support IPWSO’s work to ensure that everyone across the world has equal access, through our advice line, to expert assistance, knowledge and support about the care and treatment of people with PWS.

Attendance at Educational Conferences – Educational Outreach - this fund represents monies received from the healthcare industry to support IPWSO’s presence at PWS related international conferences. Support is provided for project management costs, educational material costs, exhibition costs, postage and travel costs.

Diagnostic Testing – this fund represents monies raised from OT4B and from fundraising campaigns and is used to support diagnostic testing for PWS.

6th International PWS Caregivers’ Conference in Berlin (PPC 2024) – this fund represents sponsorship donations associated with the conference, and also includes funds provided by Friends of IPWSO (USA) to support project management, administrative costs, delegate registration fee and travel costs for those for whom costs would be prohibitive.

Consultancy – this fund represents monies received from a private, anonymous donor for the purpose of obtaining professional advice on fundraising.

Mental Health ECHO® – this fund represents monies received from Friends of IPWSO (USA) and from the healthcare industry to support the provision of online educational workshops specifically in relation to PWS and mental health and behaviour, and also to support the purchase of computer hardware.

European Congress of Endocrinology 2023 – this funds represents monies received from the ESE Patient Advocacy Group to attend the European Congress of Endocrinology in Turkey in May 2023.

CRM System – this fund represents monies received from Friends of IPWSO (USA) to support a new customer relationship management system.

Friends translations – this fund represents monies received from Friends of IPWSO (USA) to translate educational materials into various languages and to provide interpreters at international meetings.

Friends pakistan conference – this is a grant to support a conference focused on Prader-Willi Syndrome to be held in Pakistan.

Friends meetings and workshops – funding from Friends of IPWSO (USA) to fund costs associated with the 3rd PWS International Symposium in Columbia.

Friends 2024 3-year Grant Scheme – this fund represents funds provided by Friends of IPWSO (USA) for projects to be decided upon by the IPWSO Grants Committee to include conferences, workshops, meetings, small projects and travel fellowships for the three year period commencing 2024; \$5,000 each year is to be used for project management costs.

Microgrants – this fund represents monies received from Friends of IPWSO (USA) to support smaller projects, initiated by groups, PWS associations and interested parties that will be of benefit to people living with and affected by PWS.

Friends: travel scholarship PCC – this fund represents monies for travel scholarships for delegate attendance at the 15th Congress of the African Society of Paediatric and Adolescent Endocrinology (ASPAE 2024) in Algiers, Algeria.

Friends: filming PPC 2024 conference – this fund represents monies carried forward from 2023 (\$4,800)



**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

**NOTES TO THE FINANCIAL STATEMENTS  
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**13. STATEMENT OF FUNDS (CONTINUED)**

for the production of educational resources arising from the conference in Berlin.

Friends Strategic Grants – this grant represents monies to support travel fellowships for attendance at the United in Hope: PWS 2025 International Conference in Arizona, USA in 2025.

Translation and Interpretation Fund – this fund represents funds received from Acadia Pharmaceuticals in 2024 for the purposes of translating updates to our Clinical and Scientific Consensus documents in 2025.

Funds to support the IPWSO Caregivers’ Forum – this fund represents monies to support the organisation of a Caregivers Forum, a new initiative launched in 2024.

Other funding for travel for 12th International Conference (USA) – this fund represents monies to support travel to PWS 2025 from other sources.

Raising Awareness – funds received from Friends of IPWSO USA including improvements to website functionality and preparing leaflets and collateral, including translations.

Transfers between funds have been made to compensate restricted funds where expenditure exceeds available restricted funds and where, at the agreement of the funder, restricted funds have been reassigned to another purpose or added to unrestricted funds.

**14. ANALYSIS OF NET ASSETS BETWEEN FUNDS**

**ANALYSIS OF NET ASSETS BETWEEN FUNDS - CURRENT PERIOD**

	<b>Restricted funds 2024 \$</b>	<b>Unrestricted funds 2024 \$</b>	<b>Total funds 2024 \$</b>
Current assets	159,277	302,535	<b>461,812</b>
Creditors due within one year	(5,758)	(8,389)	<b>(14,147)</b>
<b>TOTAL</b>	<u>153,519</u>	<u>294,146</u>	<u><b>447,665</b></u>

**ANALYSIS OF NET ASSETS BETWEEN FUNDS - PRIOR PERIOD**

	<b>Restricted funds 2023 \$</b>	<b>Unrestricted funds 2023 \$</b>	<b>Total funds 2023 \$</b>
Current assets	74,942	347,877	422,819
Creditors due within one year	-	(10,299)	(10,299)
<b>TOTAL</b>	<u>74,942</u>	<u>337,578</u>	<u>412,520</u>

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**INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION**

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**15. PENSION COMMITMENTS**

The CIO operates a defined contribution pension scheme. The assets of the scheme are held separately from those of the CIO in an independently administered fund. The pension cost charge represents contributions payable by the CIO to the fund and amounted to \$3,443 (2023 - \$2,151). \$640 (2023 - \$453) were payable to the fund at the balance sheet date and are included in creditors.

**16. VOLUNTEERS**

The hours committed by volunteers far outstrip the number of hours worked by paid staff members and IPWSO remains hugely grateful for their time, expertise and support. Volunteers spent 7,199 hours compared with 4,900 hours by staff.

**17. RELATED PARTY TRANSACTIONS**

During the year, donations totaling \$654 were received from 3 trustees and \$21,710 from our Honorary President, Jean Phillips Martinsson. There are no conditions attached to these donations.