www.ipwso.org

IPWSO
International
Prader-Willi Syndrome
Organisation

# ANNUAL REPORT 2024

## Vision

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

## Mission

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 with people with PWS.

Registered as a charity in England and Wales, number 1182873.

# CONTENTS

## President's report: Prof Tony Holland

This has been a year of increasingly striking contrasts. As with previous years, we have continued to be made aware of the marked inequalities that exist globally with respect to the diagnosis and support of people with PWS. At the same time, we are seeing in other parts of the world very positive developments, with considerable resources being devoted to clinical trials, thereby bringing closer the possibility of new treatments. IPWSO has to straddle this divide, trying to find ways of reducing the global inequalities and, at the same time, supporting and advocating for new treatments.

To address the challenge of global inequalities, we have worked hard to increase our contacts in Africa and in countries of the Middle East. Thank you to those families and professionals from various countries in these regions who have made this possible. We have also worked closely with pharmaceutical companies planning or undertaking trials. In partnership with the Foundation for PWS Research (FPWR), we have prepared an advisory paper on the challenges associated with undertaking trials. To better understand barriers to treatment we have investigated the extent to which growth hormone is available and affordable so we can find ways of ensuring any new treatments will be widely available. The findings from this study will be published during 2025. We will also launch "*Improving mental health and well-being for people with Prader-Willi syndrome*" at the **United in Hope: PWS International Conference**.

Through our Summit Meetings, Consultation Meetings, educational outreach activities and our Research and Clinical Trials Update Meeting we have engaged with the global PWS community. In addition, the Professional Providers and Caregivers Board (PPCB), Famcare, and the Clinical and Scientific Advisory Board (CSAB) have continued to be active organising events and providing guidance. Thank you to the members of these Boards, to Trustees, and to our advisors and most especially to the IPWSO staff for the support that they give to all these activities.

In 2025 Marguerite Hughes our CEO leaves and our new CEO, Margaret Walker, starts. Marguerite has been central to the work of IPWSO and has been key to its development over the last few years. She will be very much missed. Margaret brings considerable experience in the charitable sector, particularly in Europe, and we look forward to her guiding IPWSO in the future. In 2025 there is the excitement of the international meeting in June in partnership with PWSA |USA and FPWR. I finish my term as President at that meeting and a new President will be voted in. Finally, I would like to acknowledge the work of Dr Ellie Smith who died in 2024. As a geneticist working in Australia, she had been involved with IPWSO from the beginning and a great supporter of all that IPWSO has done over the years. She will be greatly missed.

## Chief Executive Officer’s report: Marguerite Hughes

Continuity and change go hand in hand in IPWSO, although some years one comes to the fore more than the other.

In 2024, continuity was on display in the ongoing dedication of our volunteers and their unwavering commitment to a core set of values. Continuity was also evident in both the challenges and achievements reported by families around the world.

IPWSO’s survey on access to growth hormone treatment received responses from over 80 countries, highlighting the global PWS community’s strong commitment to collaboration.

While 2024 may have been marked by continuity, 2025 looks to be a year of change.

While nothing is guaranteed, there is a possibility that the first new treatment for PWS since growth hormone, introduced 25 years ago, may be approved. If approved, we can expect access and availability to become a major topic in our community.

In 2025 IPWSO will co-host the United in Hope: PWS International Conference in partnership with PWSA | USA and FPWR. Our hope is that it will produce a positive legacy, not only for those who attend, but also for the broader PWS community.

More than half of IPWSO’s Trustees, including our longstanding President, Tony Holland, will stand down in June. They will all be greatly missed and it is particularly difficult to imagine IPWSO without Tony’s unifying presence. We are delighted that Tony has already agreed to remain an active IPWSO volunteer after his term as President concludes.

At the time of writing, a new CEO, Margaret Walker, has been recruited and will soon be joining us. She will bring with her a wealth of experience and impressive credentials and I feel certain that she will be a tremendous asset to IPWSO in the coming years. I look forward to remaining part of our community as an IPWSO volunteer.

I am ending 2024 full of hope for the global PWS community and for IPWSO. While we face ongoing challenges in raising funds, IPWSO has an outstanding network of dedicated volunteers, a small but excellent staff team, a positive reputation, and robust governance structures that together enable it to achieve a meaningful impact.

Thank you to the donors, volunteers, staff, and supporters who have enabled IPWSO’s work in 2024 and made my job such a pleasure.

# 2024 IN NUMBERS

**100**

Advice line enquiries received from 40 countries

**47**

Members and contacts in over 120 countries

**7,199**

Volunteer hours

**9**

Conference grants awarded

**10**

Small project grants awarded

**20,864**

YouTube views

**17**

Diagnostic tests provided

**4**

Educational outreach conference visits

**10**

Travel fellowships awarded

**137**

People attended online meetings

**130**

Delegates from 20 countries attended the 6th International PWS Caregivers' Conference in Berlin.

# FINANCIAL INFORMATION

## Treasurer's Report: Craig Moore

### Acknowledgement

As I reflect on this year, I have some sadness that my time on the IPWSO Board is coming to an end. It has been a privilege to serve IPWSO over the past 3 years and to work with very dedicated and committed volunteers and staff. I want to record my thanks to Tünde Liplin, Vice Chair of the Finance Committee, who acted in my stead during a few periods of my absence. Tünde will take up the role of Chair in June. With a strong background in finances, Tünde is ideally placed to lead the committee through this period of change and into what I am confident will be a period of financial growth and development. I also wish to record my thanks to Tony Holland, Marguerite Hughes, Joan Gardener, Michelle Torbert and Nora McNairney and to colleagues on the Investment and Fundraising Committees.

The Finance Committee met on 10 occasions over the past year and considered various matters including reinvestments, recruitment, insurances, and conference budgets. A development of the Finance Committee this past year was a reporting dashboard. While this is not new in financial reporting, it has made it easier for Board members from non-finance backgrounds to understand IPWSO's finances. My thanks again to Tünde and Nora for developing this tool.

We continue to manage our budget in two distinct groups; Restricted Budget, where the income generated by grants and donations is associated with specific projects and initiatives and Unrestricted Budget, where the income is allocated according to the priorities of the Board.

**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).

Our closing balance at the end of December 2024 is $447,665 (2023: 412,520) and we maintained the following balances in the bank accounts:

IPWSO's bank balances at the end of December 2024:

GBP – 31,285
EURO – 49,778
USD – 100,973
Investment Account 1 (12 months - 4.34%) - GBP 50,000 maturing 22 January 2025
Investment Account 2 (6 months – 4.50%) - GBP 112,635 maturing 22 January 2025
Investment Account 3 (12 months – 4.37%) – GBP 50,000 maturing 14 May 2025

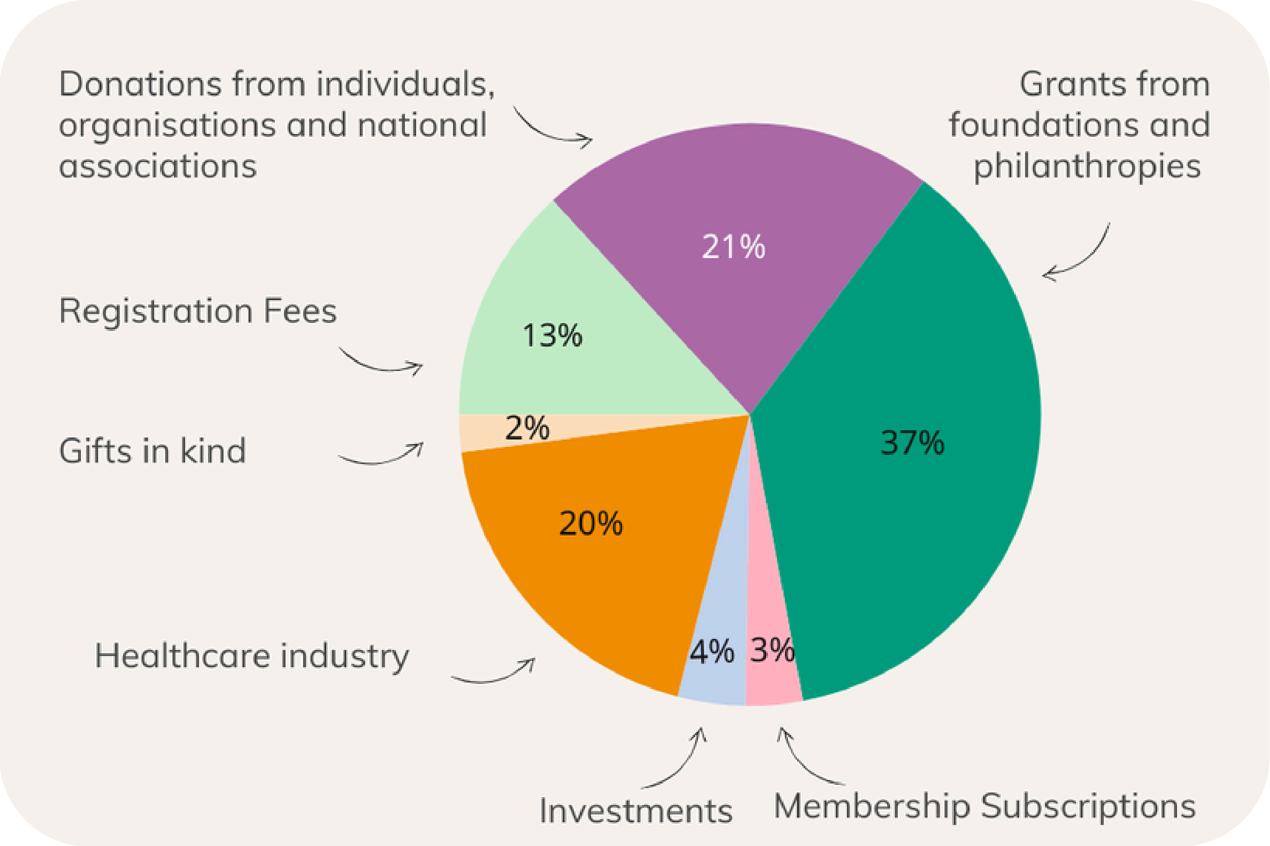
We were fortunate that our restricted income was significantly enhanced by a one-off anonymous donation of $100,000 which was provided through Friends of IPWSO (USA). We are indebted to this individual. Their generosity allows IPWSO to commit to awarding grants for small projects, and conferences and workshops for the next 2 years; a special mention of thanks is due to Friends of IPWSO (USA) whose fundraising efforts are unsurpassed. Sincere thanks are due also to all our benefactors, without whose continued support and commitment we could not fulfil our obligations to the global PWS community. We are grateful to our healthcare industry partners, member associations and individual donors and our Honorary President, Jean Phillips-Martinsson, who has been unwavering in her support. Efforts continue to increase our unrestricted income which remains a constant challenge.

## 2024 Funding Sources and Breakdown

In 2024 IPWSO received funding from the following sources:

1. Foundations and philanthropies
2. The healthcare industry
3. Donations from individuals, organisations, and national associations*
4. Registration fees
5. Investments
6. Membership subscriptions from national associations
7. Gifts in kind

*Donations listed above include monthly donations from Jean Phillips-Martinson of $21,710.



The following pharmaceutical industry partners provided support to IPWSO in 2024:

Acadia Pharmaceuticals
Palobiofarma
OT4B
Harmony Biosciences
Novo Nordisk A/S

The percentage of IPWSO's income provided by industry partners in 2024 was 20% (2023 = 25%).

### How we use our funds

Our restricted funds supported a wide range of activities over the year including our advice line, educational outreach, diagnostic testing, grants for small projects, conferences, workshops, and travel scholarships for delegates attending the 16th Congress of the African Society of Paediatric and Adolescent Endocrinology (ASPAE 2024) in Algiers, Algeria, and the 6th International PWS Caregivers' Conference in Berlin. Unrestricted income primarily supported office running costs, staffing, insurances and costs associated with financial reporting requirements of the Charity Commission and the virtual finance office.

The attached Financial Statements provide fuller details.

### Major Donors and sponsors

Friends of IPWSO (USA)
Jean Phillips-Martinsson
Acadia Pharmaceuticals
Palobiofarma
OT4B
Harmony Biosciences
Novo Nordisk A/S

# FRIENDS OF IPWSO (USA)

IPWSO is grateful to Friends of IPWSO (USA) for their regular support to help us improve the lives of people with Prader-Willi syndrome and inform those who support them. Without generous grants from Friends of IPWSO (USA) none of the projects listed here would have been possible in 2024.

**Educational outreach:** Funding enabled IPWSO representatives to attend the 15th Congress of the African Society for Paediatric and Adolescent Endocrinology in Algiers, Algeria (ASPAE 2024). Project management costs were also supported.

**Support for small projects:** This funding enabled research projects to be carried out at Aster CMI Hospital, Bengaluru (Bengaluru (Bangalore)), India, and at the University Kebangsaan Malaysia, web development for the PWS Association in Costa Rica, a PWS camp in Portugal, and the translation of educational materials initiated by SPW Brasil and Egypt. Project management costs were also supported.

**Support for travel fellowships:** This funding supported travel fellowships for 5 professionals from African countries to attend ASPAE 2024, 5 delegates, parents, and professionals, to attend the 6th International PWS Caregivers' Conference in Berlin and also a speaker to present at the National Alliance of Rare Diseases International Conference in Bulgaria. Project management costs were also supported.

**Support for conference and workshops:** Funding was provided for conferences held in person and online in Bulgaria, China, India, Mexico, and New Zealand. Project management costs were also supported.

**Support for production of educational materials:** Videos and reports arising from the 6th International PWS Caregivers' Conference in Berlin were compiled and made freely available on IPWSO's YouTube channel.

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

### 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.

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

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

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

| | Note | Restricted funds 2024 $ | Unrestricted funds 2024 $ | Total funds 2024 $ | Total funds 2023 $ |
|---|---|---|---|---|---|
| **INCOME FROM:** | | | | | |
| 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 |
| **TOTAL INCOME** | | **189,243** | **118,884** | **308,127** | 208,262 |
| **EXPENDITURE ON:** | | | | | |
| Charitable activities | 5 | **145,225** | **127,757** | **272,982** | 202,956 |
| **TOTAL EXPENDITURE** | | **145,225** | **127,757** | **272,982** | 202,956 |
| **NET INCOME/(EXPENDITURE)** | | **44,018** | **(8,873)** | **35,145** | 5,306 |
| Transfers between funds | 13 | **34,559** | **(34,559)** | **-** | - |
| **NET MOVEMENT IN FUNDS** | | **78,577** | **(43,432)** | **35,145** | 5,306 |
| **RECONCILIATION OF FUNDS:** | | | | | |
| Total funds brought forward | | **74,942** | **337,578** | **412,520** | 407,214 |
| Net movement in funds | | **78,577** | **(43,432)** | **35,145** | 5,306 |
| **TOTAL FUNDS CARRIED FORWARD** | | **153,519** | **294,146** | **447,665** | 412,520 |

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.

## BALANCE SHEET
## AS AT 31 DECEMBER 2024

| | Note | | **2024**<br>**$** | | 2023<br>$ |
|---|---|---|---|---|---|
| **CURRENT ASSETS** | | | | | |
| 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) | |
| **NET CURRENT ASSETS** | | | **447,665** | | 412,520 |
| **TOTAL NET ASSETS** | | | **447,665** | | 412,520 |
| **CHARITY FUNDS** | | | | | |
| Restricted funds | 13 | | **153,519** | | 74,942 |
| Unrestricted funds | 13 | | **294,146** | | 337,578 |
| **TOTAL FUNDS** | | | **447,665** | | 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.

## 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.

## 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.

## 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.

## 2. INCOME FROM DONATIONS

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

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

## 3. INCOME FROM CHARITABLE ACTIVITIES

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

## 4. INVESTMENT INCOME

| | **Unrestricted funds 2024 $** | **Total funds 2024 $** | Total funds 2023 $ |
|---|---|---|---|
| Money market interest | 11,637 | **11,637** | 4,528 |
| TOTAL 2023 | 4,528 | 4,528 | |

## 5. ANALYSIS OF EXPENDITURE BY ACTIVITIES

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

### ANALYSIS OF DIRECT COSTS

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

## 5. ANALYSIS OF EXPENDITURE BY ACTIVITIES (CONTINUED)

### ANALYSIS OF SUPPORT COSTS

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

## 6. ANALYSIS OF GRANTS

| | **Grants to Institutions 2024 $** | **Grants to Individuals 2024 $** | **Total funds 2024 $** | Total funds 2023 $ |
|---|---|---|---|---|
| Microgrants | 5,147 | 1,583 | **6,730** | 7,899 |
| TOTAL 2023 | 6,437 | 1,462 | 7,899 | |

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

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

## 7. INDEPENDENT EXAMINER'S REMUNERATION

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

## 8. STAFF COSTS AND KEY MANAGEMENT PERSONNEL

| | **2024**<br>**$** | 2023<br>$ |
|---|---:|---:|
| Wages and salaries | **106,690** | 113,233 |
| Social security costs | **3,502** | 3,746 |
| Contribution to defined contribution pension schemes | **3,443** | 2,151 |
| | **113,635** | 119,130 |

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

| | **2024**<br>**No.** | 2023<br>No. |
|---|---:|---:|
| Staff | **4** | 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

| | **2024**<br>**$** | 2023<br>$ |
|---|---:|---:|
| Trade debtors | **4,000** | 17,776 |

## 11. CURRENT ASSET INVESTMENTS

| | **2024**<br>**$** | 2023<br>$ |
|---|---|---|
| Money market investments (maturing between 6 months and 1 year) | **266,141** | 207,057 |

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

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

| | **2024**<br>**$** | 2023<br>$ |
|---|---|---|
| Deferred income at 1 January 2024 | **163** | - |
| Resources deferred during the year | **-** | 163 |
| Amounts released from previous periods | **(163)** | - |
| | **-** | 163 |

Deferred income represents 2024 membership fees received in advance.

## 13. STATEMENT OF FUNDS

### STATEMENT OF FUNDS - CURRENT YEAR

| | Balance at 1 January 2024 $ | Income $ | Expenditure $ | Transfers in/out $ | Balance at 31 December 2024 $ |
|---|---|---|---|---|---|
| **UNRESTRICTED FUNDS** | | | | | |
| General Funds | 337,578 | 118,884 | (127,757) | (34,559) | 294,146 |
| **RESTRICTED FUNDS** | | | | | |
| 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 |
| | 74,942 | 189,243 | (145,225) | 34,559 | 153,519 |
| **TOTAL OF FUNDS** | 412,520 | 308,127 | (272,982) | - | 447,665 |

## 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 $ |
|---|---|---|---|---|---|
| **UNRESTRICTED FUNDS** | | | | | |
| General Funds | 368,878 | 62,768 | (116,277) | 22,209 | 337,578 |
| **RESTRICTED FUNDS** | | | | | |
| 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) | - |
| | 38,336 | 145,494 | (86,679) | (22,209) | 74,942 |
| **TOTAL OF FUNDS** | 407,214 | 208,262 | (202,956) | - | 412,520 |

## 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.

Micrograntes – 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)

## 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

| | **Restricted funds 2024 $** | **Unrestricted funds 2024 $** | **Total funds 2024 $** |
|---|---|---|---|
| Current assets | 159,277 | 302,535 | **461,812** |
| Creditors due within one year | (5,758) | (8,389) | **(14,147)** |
| **TOTAL** | 153,519 | 294,146 | **447,665** |

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

| | Restricted funds 2023 $ | Unrestricted funds 2023 $ | Total funds 2023 $ |
|---|---|---|---|
| Current assets | 74,942 | 347,877 | 422,819 |
| Creditors due within one year | - | (10,299) | (10,299) |
| **TOTAL** | 74,942 | 337,578 | 412,520 |

## 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.

# ENVIRONMENTAL SUSTAINABILITY

IPWSO's commitment to environmental sustainability continued in 2024 following our signing of the Climate and Environmental Leadership Principles formulated by the Association of Chief Executives of Voluntary Organisations (ACEVO) in the UK in 2023.

During 2024, Marguerite Hughes continued to serve as a member of ACEVO's Climate Working Group and to learn from the experiences of other charities, both those with an explicit environmental remit and others, like IPWSO, that do not.

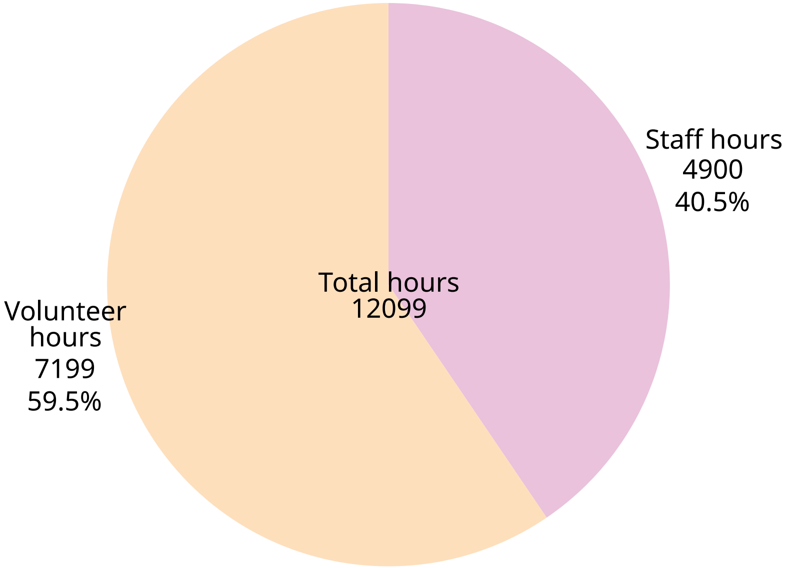
The discussions in that group reinforced the idea that IPWSO may achieve a greater positive environmental impact by using its platform to raise awareness of environmental sustainability rather than by focusing exclusively on measuring or reducing its own environmental impact, which remains small.

Throughout 2024, IPWSO grant schemes required applicants to comment on the anticipated environmental impact of the projects they proposed and how they might mitigate any negative environmental effects.

Steps were also taken to reduce the environmental impact of the 6th International PWS Caregivers' Conference in Berlin.

# VOLUNTEERS

As in previous years, the hours committed by IPWSO volunteers far outstrips the number of hours worked by paid staff.



# NOMINATIONS COMMITTEE

IPWSO's Nominations Committee, chaired by our Legal Advisor, Colin Pearson, met regularly throughout 2024. Its brief was to prepare a slate of recommended candidates for the positions of IPWSO President and Trustees for consideration by the Board of Trustees, prior to a final slate being presented to the General Assembly in June 2025.

The candidates approved by the General Assembly will form IPWSO's Board of Trustees for the period from 2025 to 2028.

The closing date for receipt of applications was 14 October 2024. Although it made their task of selecting candidates particularly difficult, the Nominations Committee was delighted with the number and quality of applications received from around the world.

The recommended slate of candidates will be distributed to IPWSO's member organisations for their consideration in advance of the General Assembly in June.

# ADVISORY BOARDS

## Clinical and Scientific Advisory Board: Dan Driscoll, MD, PhD

**Membership of CSAB:**

The membership of the CSAB consists of 17 health care professionals from a variety of specialties including medical genetics, developmental paediatrics, paediatric and adult endocrinology, clinical psychology, general paediatrics, internal medicine, psychiatry, gastroenterology, and orthopaedic surgery. In addition, the CEO of IPWSO serves as an ex officio member.

One new member was added this year – Constanze Lämmer, who is a paediatric endocrinologist and nutritionist. In the next year we hope to add a neonatologist to our Board.

**Scientific papers:**

The CSAB has continued to prepare pdf files listing scientific papers published over the previous three-month period in peer reviewed journals. These lists have been circulated widely at the international level by the IPWSO office. The range of research being published is extensive and includes basic science and a broad range of clinical topics from genetics to endocrinology, to behaviour and mental health. There are papers reporting on clinical trials of specific interventions and the application of some of the advanced neuroimaging techniques. A special note of thanks goes out to Joyce Whittington for her help in preparing this material.

The quarterly collection of papers is available on our website: https://ipwso.org/information-for-medical-professionals/research-papers/

**Advice:**

The CSAB has continued to respond to requests for advice from families and health care professionals around the world.

**United in Hope: PWS International Conference:**

The CSAB is preparing to run another successful Clinical and Scientific (C&S) meeting as part of the United in Hope: PWS International Conference in Phoenix, Arizona, USA in June 2025. The conference is in partnership with PWSA | USA and FPWR. The C&S meeting is the premier and best attended PWS international clinical and scientific meeting in the world. We anticipate that the 2025 meeting will be the most robust and best attended C&S meeting to date given the partnership among the 3 PWS patient advocacy groups (IPWSO, PWSA | USA, and FPWR).

The C&S Programme Committee has had several meetings so far and lined up 4 invited speakers. The committee looks forward to reviewing abstract submissions received from across the globe for oral and poster presentations.

**Consensus documents:**

Consensus overview and treatment guidelines for Adults, Adolescents, Children, and Infants were first done in 2018. We are now updating them. To date, the adult document has been updated and approved by the CSAB.

## Famcare Board: Verena Gutmann

Famcare is proud that our board members well represent our global PWS community coming from Australia, Austria, Colombia, Denmark, Ireland, and South Africa. Recently we were happy to welcome Karen O'Reilly, a mother from New Zealand, and Liane Mufarrej Motta, President of SPW Brasil. Despite the challenges of our many different time zones, the Board met regularly throughout the year via Zoom.

Famcare has been invited to contribute to the Family Programme at the **United in Hope: PWS International Conference** in Arizona in 2025 and we will be pleased to present on the work of our Board. We were also pleased to attend the 6th International PWS Caregivers' Conference in Berlin in May 2024. Attending conferences contributes towards IPWSO's mission of facilitating peer learning and strengthens our community around the world.

We held our 3rd Family webinar entitled **"Progressing from Childhood to Adulthood"** via Zoom in November 2024. We had presentations from a variety of speakers, and video recordings were later made available on the IPWSO website. We then had time for discussion providing an opportunity for parents and caregivers to speak in a safe environment about the challenges posed when things change - decision-making; relationships and sexuality; moving from the family home to other settings; the challenges of the caregiver role and the pros and cons of living and working from home. We exchanged different experiences, differing perspectives and we all came away enriched and feeling supported and more open to different strategies to successfully manage PWS, - a genetic disorder with similar characteristics but with very different, individualised outcomes.

Famcare also produces guidance documents, and these are available on the IPWSO website.

## Professional Providers and Caregivers Board: Lynn Garrick

2024 was an exciting year for global caregivers, highlighted by the 6th International Caregivers' Conference held in Berlin, Germany. This remarkable event brought together over 130 delegates from 20 countries. In-person conferences are always special moments to collaborate, learn, and forge new friendships with others who share a deep passion for supporting individuals with Prader-Willi syndrome (PWS). The conference featured a wide array of lectures, workshops, and poster presentations, all designed to benefit both care providers and the individuals they serve.

A significant milestone during this meeting was the launch of the IPWSO Caregivers' Forum, a global virtual space for professional caregivers worldwide. This platform allows participants to connect, collaborate, and share best practices and knowledge, ensuring that individuals with PWS are empowered to live fulfilling and autonomous lives. Since its inception, over 100 caregivers have joined the group, and we are eager to expand this network of dedicated PWS caregiving experts.

Following the Berlin conference, plans are already underway for the International PWS Conference, scheduled for June 25–28, 2025, in Phoenix, Arizona. This upcoming event promises to be particularly exciting as it will unite three PWS organizations—IPWSO, PWSA | USA, and FPWR—for one extraordinary gathering.

Meanwhile, our board members continue to work on a variety of initiatives throughout the year aimed at supporting the caregiving community and those we serve. We remain steadfast in our commitment to providing the resources and tools needed to ensure informed and exceptional care.

It is my great privilege to collaborate with a team of knowledgeable, dedicated, and passionate individuals on the PPCB board: Patrice Carroll, Larry Genstil, Neil Gumley, Norbert Hödebeck-Stuntebeck, Laura Keane, Hubert Soyer, Mary K. Ziccardi, and Shelly Cordner from the IPWSO office, who provides invaluable support.

We extend a heartfelt invitation to join us at the 2025 International PWS Conference in Phoenix. It will undoubtedly be another enriching experience for everyone involved in the global caregiving community.

# OUR PROJECTS

## Grant Awards: Lynn Garrick

*"Having this [dedicated PWS] website [available] in Costa Rica will make it easier for other families like ours to learn about the syndrome and connect with more people who have it, so we can have a support network. For a long time, we thought we were the only ones, and now we will have the opportunity to come together and fight for a common purpose."*

Diana Alpizar, mother, ASPORAWI, Costa Rica PWS Association – Microgrant 2024 Recipients

*"ASOPRAWI has been a dream come true for me. For many years I longed to meet another family with a child with PWS."*

Laura, mother. Costa Rica PWS Association – Microgrant 2024 Recipients

*"I left the Conference [PWS PPC Conference, Berlin] feeling connected, empowered and with fresh ideas."*

Bjørn Christensen, Community Connections, New Zealand,
- IPWSO Travel Fellowship Recipient

*"After returning to my country, I gathered the knowledge I had gained about behaviours and ABA therapy and shared it with teachers and clinical staff. In addition, I will share useful information with the PWS Vietnam Parents Association equipping parents with new knowledge as well as updates on treatments and methods …"*

Van, Dinh Thi Thanh (pictured), Psychologist, Morning Star Centre, Vietnam
– IPWSO Travel Fellowship Recipient

This was a busy year for the Grants Committee. We received very many worthy applications for conferences and workshops, small projects, and travel scholarships. Assessing the applications falls to the Grants Committee Members who are guided by our assessment and priority criteria, which is underpinned by a desire to promote equal opportunities and help build and strengthen PWS communities across the globe. I am hugely grateful to Susanne Blichfeldt, Norbert Hödebeck-Stuntebeck, Svetlana Labun, Georgina Loughnan and IPWSO office member, Nora McNairney, for their time and diligence in our deliberations.

We committed a total of $83,000 to various projects that took place in 2024 or will take place in early 2025. Our ability to make these awards is due to the generosity of Friends of IPWSO (USA) and their tremendous fundraising efforts, and this year, a one-off anonymous donation of $100,000; a wonderful gift that will no doubt make a great impact on the lives of many of our loved ones living with PWS across the world.

PWS Associations in México, Bulgaria, New Zealand, China, and India held conferences, and PWS Colombia, APPW-Portugal and groups in Kenya and Côte d’Ivoire will host events in 2025. We are particularly pleased to support PWS activities on the African continent as our intelligence indicates little awareness of the syndrome and challenges around accessing supports and treatments.

Our small project grant scheme was premised on the belief that families and professionals are best able to identify projects that will be of benefit to them and their local communities, and this has been demonstrated by the high level of interest shown and the variety of projects proposed. Grants are awarded up to the value of $2,000.

SPW Brasil and PWSA Egypt-ME received funding to translate educational materials into their local languages. ASOPRAWI, (Costa Rica PWS Association), developed a dedicated PWS website, and medical professionals from the Universiti Kebangsaan Malaysia (UKM) and Aster CMI hospital, Bengaluru, India, used their funds to undertake research projects. The Associação SPW in Portugal held their first ever holiday camp for people of all ages with PWS, which was an excellent achievement and a big success.

By establishing this scheme, we have enabled more underserved groups to commit to small, manageable projects that can be of huge benefit to their local PWS community. There are no restrictions on the types of projects that are considered for funding other than the expectation that projects will be of benefit to more than one family, are concerned with building the capacity of networks or individuals to support people with PWS or which involve activities that are expected to directly assist people with PWS and their families.

We allocated $41,000 to travel scholarships enabling delegates to attend conferences including the 15th Congress of the African Society for Paediatric and Adolescent Endocrinology (ASPAE) in Algiers, the 6th International PWS Caregivers' Conference in Berlin and also our United in Hope: 2025 International Conference in Arizona, where we look forward to welcoming new PWS contacts including Association leads and medical professionals from Latin America, Europe, Africa and Asia. These individuals are key to growing our community and to increasing our understanding of PWS across the world.

To stay informed of new grant rounds in 2025, sign up to receive the IPWSO newsletter or visit our website: https://ipwso.org/how-we-can-help/support-for-conferences-and-workshops/. We look forward to supporting many more initiatives in 2025.

## United in Hope: PWS International Conference: Nora McNairney

One of the focal points of IPWSO's work is the International Conference, a unique and immersive event that brings together the global PWS community – medical professionals, families, professional caregivers and people with PWS of all ages - with the aim of networking, sharing knowledge and enabling a better understanding of the needs of people with the syndrome. This will be IPWSO's 12th International Conference, and we are particularly excited to be co-hosting with PWSA | USA and the FPWR. Our theme **"United in Hope"** reflects this unique collaboration, which we expect will result in the largest international PWS conference ever held.

The conference will take place from 24-28 June 2025 at the Arizona Grand Resort and Spa, Phoenix, Arizona, USA. Throughout 2024, the various committees – the PWS 2025 Steering Committee, the Clinical and Scientific Programme Committee, the Family Committee and the Professional Providers and Caregivers Programme Committee - have been meeting to fulfil their briefs. The committees have worked diligently to identify a wide range of topics that will be of interest to a global multidisciplinary audience as well as to people living with PWS, their families, carers and all those providing a holistic approach to supporting the health, education and social care requirements of people living with the syndrome. Expert speakers have been identified who can present the most current thinking and facilitate what will no doubt lead to interesting debates and discussions.

Thanks to Friends of IPWSO (USA), IPWSO has offered travel fellowships to people who would not otherwise be able to attend the conference, including medical professionals, parents and PWS Association representatives from Asia, Africa, Europe, and Latin America. Sponsorship from the healthcare sector enhances the conference and helps bridge the gap between our moderately priced registration fees and the actual conference costs and we are indebted to pharmaceutical companies and also independent donors and PWS Associations and Chapters.

Full details on how to register and book accommodation are available on the IPWSO website.

The countdown is now on, and we look forward to meeting you in Arizona very soon.

## Educational outreach

*"I was the only Ethiopian to participate in this conference, and I am sure we have been missing many children with PWS. I am very grateful to IPWSO for giving me this opportunity, and I will use this knowledge throughout my career."*

Dr Hiwot Nida, Paediatric Endocrinologist – ASPAE 2024

*"After the various presentations, a debate was held with [PWS] parents about their experiences and the difficulties they encountered. This allowed us to get close to the pathology that we believe does not exist in our context, to see the children and the typical phenotype of PWS in person (which we see only in the books), to perceive more closely the concerns, the experiences, littered with the ups and downs of the parents. We greatly thank the organising committee for planning such a topic."*

Dr Adele Chetcha Bodieu, Paediatric Endocrinologist, Central Hospital, Yaoundé,
Cameroon & ASPAE Vice President

Attendance at educational conferences is an important way in which IPWSO promotes equal opportunities and helps grow and strengthen our PWS community. Hosting an exhibition table provides an excellent opportunity for us to engage with medical professionals who may have little knowledge of PWS and also those who may be actively involved in supporting people with the syndrome. It is a learning experience for all participants; we get to raise awareness of IPWSO and how we can be of help, and we learn about the challenges faced by many underserved populations, which makes us acutely aware of how much more we need to do! We also endeavour to present the latest PWS thinking, research and findings at symposia, workshops and via poster displays.

This year we attended four conferences attracting for the most part paediatric and adolescent endocrinologists and child neurologists, although delegates also included professionals from speech therapy and psychiatry, and general clinicians.

At the 15th Congress of the African Society for Paediatric and Adolescent Endocrinology (ASPAE) in Algiers in March, our Vice President, François Besnier, CSAB Member, Maithé Tauber, and volunteer, Marie-Odile Besnier, delivered a presentation entitled *"Understanding PWS for Better Support"*. This session was conducted in French and Arabic to around 37 families.

At the plenary session Maithé Tauber presented on the *"Management of PWS"* and Asmahane Ladjouze, President of the Société Algérienne d'Endocrinologie et Diabétologie Pédiatrique (SAEDP) presented a paper on PWS in Algeria.

Thanks to Friends of IPWSO (USA) we provided five travel scholarships that enabled doctors from Nigeria, Ethiopia, Kenya and Cameroon to attend ASPAE 2024; our Vice President met with each to explore how IPWSO can collaborate in order to raise awareness of PWS in their countries and we hope to some manifestations of this work in 2025.

In May, Karin Clarke, IPWSO Trustee and Chair of PWS Support (South Africa) and Dr Engela Honey, IPWSO Advisor, secured our presence at the International Child Neurology Conference in Cape Town. Over 850 delegates attended the event from all parts of the world including China, India, Türkiye, and Pakistan. Our educational materials, which are freely available on our website and which we made available on an IPWSO flash drive, were well received, particularly the one-page publication "Does Your Patient Have PWS" which is available in French, Portuguese, and Arabic.

In October, Lantz Yap, IPWSO Trustee, joined forces with Mrs Shikha Metharamani and Dr Parul from the Indian PWS Association (IPWSA) to exhibit at the Asia Pacific Paediatric and Adolescent Endocrine Society and Indian Society for Paediatric and Adolescent Endocrinology (APPES-ISPAE) Conference in New Delhi. IPWSO/IPWSA was the sole patient-led non-profit among the many pharmaceutical exhibitors. Lantz is working diligently to build IPWSO's profile in the Asia-Pacific region and is looking forward to securing our presence at APPES-ANZSPED 2026 in Australia.

In November, Tony Holland, President, Nick Finer, IPWSO Advisor, and staff member, Nora McNairney represented IPWSO at the European Society for Paediatric Endocrinology in Liverpool, UK. The meeting attracted over 3000 delegates from across the world. Many of those who visited our stand from underserved countries were pleased to learn about our free diagnostic testing service and how they can obtain diagnostic testing paper. Tony Holland and Charlotte Höybye, Member of IPWSO's Clinical and Scientific Advisory Board, gave presentations on *"Long Term Management and Outcomes in PWS"* and *"Growth Hormone Treatment in Adults with PWS,"* respectively, at a dedicated PWS symposium.

We are confident that the impact of our educational outreach activities will be evidenced in the longer term with an increase in PWS diagnosis in the targeted regions.

None of this would be possible without the financial support of the healthcare industry, Friends of IPWSO (USA) and the commitment of our PWS volunteers who willingly give of their time and expertise. We are hugely grateful for all their support.

## Online events: Karin Clarke

Another successful year of online events was hosted by IPWSO in 2024. 137 people attended people attended one or more online event. Additionally, 14 new video presentations were added to the IPWSO YouTube channel for those unable to attend or wishing to revisit the talks.

### Research and Clinical Trials Update Meeting

Our 2nd annual research update meeting was held on September 5, bringing together researchers, pharmaceutical companies, and families to discuss advancements in PWS research. Nick Finer, an IPWSO advisor, provided an overview, followed by presentations from six companies with ongoing or recently completed trials. Attendance was strong, though slightly lower than in 2023.

### IPWSO Caregivers' Forum

Launched in 2024, this new series of virtual meetings connects professional PWS caregivers globally. The inaugural meeting on September 26 featured our USA Caregiver Delegate, Mark Lister, who discussed Fostering collaboration among caregivers. Each meeting is followed up with a summary newsletter. Thanks to Latham Centers for agreeing to support the Forum and all that we do for PWS caregivers.

### Summit Meeting

On November 13, IPWSO held its third Summit Meeting, focusing on Global Access to Therapies for People with PWS: Understanding the Challenges and Seeking Solutions. It was wonderful to have Alexandra Heumber Perry, CEO of Rare Diseases International as a guest speaker. She presented on Access to Therapies for Rare Disorders in Low- and Middle-Income Countries. Our second speaker was Tony Holland, President of IPWSO, who presented early data from the recent IPWSO Study of the Global Availability of GHT. The summit underscored disparities in treatment access within the broader context of rare diseases.

### Famcare Board Family Meetings

On November 23, the Famcare Board hosted its third Family Meeting, addressing Progressing from childhood to adulthood. Held at two times to facilitate global participation, the first session featured Gary Brennan from PWSAI, Ireland, who gave a thought-provoking talk about decision making capacity for adults with PWS. Karen O'Reilly from New Zealand and Liezl Vlok from South Africa shared their family's personal experiences of their sons transitioning to care homes.

In the second session Patrice Carroll from Latham Centers, USA, spoke about relationships, followed by Amalia Balart from Chile and Verena Wanker-Gutmann from Austria sharing their experiences with adult children living at home or in residential care.

We would like to say a big thank you to the great speakers who presented at all these events, the Online Events Committee members, and Shelly Cordner from the IPWSO office for her organisation of the events.

To find out more about our events please visit: www.ipwso.org/news-events/

## Policy and research: Prof Tony Holland

### Research and Clinical Trials Committee:

In 2023 we established our Research and Clinical Trials Committee, the aim of which is to foster and facilitate research, undertake research where it is appropriate for IPWSO to do so, and to enable and encourage a wider global involvement in research and clinical trials.

### Research Meetings:

We hosted our second annual Research and Clinical Trials Update Meeting on 5 September. After an introductory talk by Nick Finer, we received an update from six companies active in PWS research. We also held our third annual Summit Meeting on Global Access to Therapies for People with PWS.

Our meetings are open to all, and contributions help to inform our policy and research. For those unable to attend online meetings on the day, recordings are made available on IPWSO's YouTube channel.

### Research

**Residential study:** Led by Brian Hughes and with the support from providers of special care services around the world, this year we concluded our research project on "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." The findings were published in the February edition of the Orphanet Journal of Rare Diseases. We concluded that full-time care services have a high likelihood of enhancing the lives of people with PWS within one year with long-lasting benefits, especially if those services are exclusive and specialised around the particular needs of PWS. This project was based on a large statistical dataset on which robust analyses of improvements in weight, BMI, and behavioural outcomes could be based. Our sincere appreciation to everyone that participated in this study.

**Growth Hormone (GH) Treatment Survey:** We know that many people with PWS cannot access GH Treatment. In 2024 we conducted a survey in order to learn more about where GH is and is not available for children and adults with PWS. We also wanted to better understand the challenges that families experience when trying to access GH Treatment. We received responses from over 80 countries, and the results of this survey are currently under analysis by Joyce Whittington. We shared some initial results at a Summit Meeting on 13 November.

**Report of the IPWSO Mental Health Network:** In addition to general and specific physical health needs, children, and adults with PWS have significant needs that arise as a consequence of the high risk of mental ill-health including the occurrence of particular behaviours of concern. It was in recognition of these needs, the absence of an agreed consensus on the assessment and treatment of mental ill-health, and concerns about the limited expertise available internationally that in 2021, we established a global mental health network comprising parents, psychiatrists, psychologists, and behaviour experts. The network has held several virtual meetings and an in-person workshop and has drawn from published research, expert published reviews and the experience of the membership of the network to compile a report entitled *"Improving mental health and well-being for people with Prader-Willi syndrome"*, which will be launched at our United in Hope: PWS 2025 International Conference.

## People with PWS Committee: Svetlana Labun

The People with PWS Committee consists of dedicated IPWSO Advisors who work closely with individuals with PWS in their daily lives. Our goal is to collaborate with people with PWS to identify the most effective ways for them to have their voices heard—whether in local group settings, through national advocacy efforts, or as part of the global IPWSO community.

Highlights included insights from a group, established in 2023, of 15 adults with PWS in North Germany. Christian Blohm spoke at the 6th International PWS Caregivers' Conference in Berlin, Germany. His presentation, titled: *"People with Prader-Willi syndrome give themselves a voice: Requirements and solutions"* detailed the group's efforts to advocate for their needs and propose solutions.

The group also championed the idea of fostering direct communication with IPWSO, extending an invitation to Trustees and Advisors for an online meeting to explore collaboration opportunities between individuals with PWS and IPWSO. This meeting, held in November, featured thought-provoking questions and ambitious ideas for the future. We eagerly anticipate continuing these important discussions.

The Australian OWLA (Our Way of Life – Australia) group, active since August 2021, played a pivotal role in shaping the conference stream for individuals with PWS at the 6th Asia Pacific PWS Conference. Eight members wrote and delivered presentations on a wide range of topics, including nutrition, staying active, employment, transitioning after school years, restrictive practices and more. These sessions sparked high levels of engagement, with question-and-discussion periods often extending well beyond the presentations themselves.

Additional insights from this region included learning about people with PWS who serve on the boards of PWS Associations or Advocacy groups. The Committee was interested in hearing how this approach has been implemented in Malaysia, Australia, and New Zealand.

We were delighted to welcome Gary Brennan to the Committee this year. Gary co-authored a report on service provision for people with PWS in Ireland emphasising the voices and experiences of people with PWS and their families. PWSAI's Advocacy group launched the national report in March, with Richard Tallon, a man with PWS, delivering a 10-minute speech written by the group. In July, adults with PWS organized a well-attended get-together with 25-30 participants. The group has also secured funding for a PWS awareness module, set to be developed starting in 2025.

A heartfelt thanks to our Committee Members, and especially to everyone with PWS who shared their thoughts and perspectives with us this year.

## International advocacy: Marguerite Hughes

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)
- Rare Diseases International (RDI)

**Key IPWSO Advocacy Activities in 2024:**

1. On 29 February we marked Rare Disease Day by sharing information and celebrating the lives of people living with rare diseases as part of this global initiative.
2. We joined the European endocrine community in celebrating European Hormone Day on 24 April.
3. IPWSO President Tony Holland continued to serve as a board member of the International Alliance of Patients' Organizations (IAPO).
4. IPWSO CEO Marguerite Hughes remained a member of the PWS Clinical Trial Consortium.
5. We joined the Federations Group of Rare Diseases International to work and learn alongside other federations that support people with rare diseases.

## Diagnostic testing: Marguerite Hughes

For the 22nd consecutive year we offered free diagnostic testing for PWS to families unable to access or afford testing in their own countries. This service was subsidised by and provided in collaboration with the Baschirotto Institute for Rare Diseases (BIRD), which is based in Vicenza, Italy.

17 diagnostic tests were completed on behalf of IPWSO in 2024. The samples came from four countries in Africa, Asia, Latin American and Eastern Europe. In total, 597 samples from 50 countries have now been tested by means of this service. Tests conducted on behalf of IPWSO in 2024 were paid for through sponsorship received from OT4B and donations made by members of the public.

The success of our diagnostic testing programme continues to rely on doctors and families knowing about the service. Regrettably, in 2024, we heard reports from some families in low-income countries who had paid high prices to send samples to private international laboratories for testing because they were unaware of IPWSO's service.

Once again in 2024 we used our social media and website to raise awareness of the service, and promoted it at relevant conferences and meetings, and in individual correspondence with families and professionals worldwide.

We received reports from doctors in some African countries that their ability to utilise the IPWSO service was hindered by a lack of availability of filter paper locally. We are now distributing free filter paper on request and hope that this will result in increased uptake of the service from these countries in the coming years.

More information about how to access the services provided by BIRD and by Instituto Fernandes Figueira, which offers free diagnostic testing for families in Latin America, is available on our website.

## Publications and Communications Committee: François Besnier

Providing current, accessible, and useful information for families, people with PWS and professionals remains of prime importance to IPWSO and is the mission of our committee and staff.

We were sorry, but happy, for Agnes Hoctor, our Communications and Fundraising Manager, who left us in January 2024 to pursue other career interests. In the absence of a new incumbent, Shelly Cordner and Nora McNairney have done a sterling job by updating the website, compiling newsletters, and continuing to produce our very valuable educational materials.

Following feedback gained during our educational outreach activities in Cameroon and Algiers, we simplified some of our publications and produced one-page leaflets on diagnosis and also on preventing obesity. We made these available in a number of languages and they have been very well received. This is in keeping with IPWSO's policy to promote equal opportunities and make information accessible in all parts of the world.

Our website developers undertook an initial review and highlighted some areas for improvement. Although global traffic to the website is increasing, most engagement comes from the USA, UK, Australia, and Canada, so there is work to be done to raise awareness more widely of this important resource.

Our communications must evolve to take into consideration how a younger demographic engages with information and social media, and we must also address how accessible our information is for people with PWS.

A new committee has now been established, and we held our first meeting in October. We are grateful for the expertise and enthusiasm that Marguerite Hughes, Brittni Kliment and Veronique Denhaerinck are bringing to the table. We have set out an action plan which will involve surveying national associations, a deeper review of the website and an assessment of our use of social media channels.

## Advice service: Marguerite Hughes

More than any other IPWSO service, our Advice Line provides a constant reminder of the struggles that people with PWS and their families face around the world.

We were particularly struck by the desperate pleas for help from one family whose loved one with PWS was in intensive care, and another whose child with PWS had been imprisoned. We were moved, too, by the appeal from a family that could not afford to pay for a necessary surgery for their young child.

As in previous years, there were many requests for help from families that wanted to leave their own countries as they feared that their children would not receive appropriate treatments or support there.

There were also many queries from families whose loved ones with PWS were struggling with obesity or experiencing significant behavioural or mental health challenges.

Some questions, such as how to access our free diagnostic testing service, were easily answered. Others required us to provide ongoing support and advice over an extended period. In a few cases we needed to meet with individual families, sometimes with interpreters present, to adequately meet their needs.

While the Advice Line highlighted many problems experienced by people with PWS worldwide, it also highlighted the strength and generosity of our volunteer network. Led by our Clinical and Scientific Advisory Board members, Dr Susanne Blichfeldt and Dr Dan Driscoll, every enquirer received a timely response from a qualified volunteer. In some cases, we were able to link enquirers to support groups or relevant professionals in their areas and in all cases, we made people aware that we would be happy to help them to the extent that we could and for as long as they needed.

In total, we responded to over 100 queries from over 40 countries in 2024.

Thank you to the medical professionals who make this service possible and to the families who put their trust in us.

# ABOUT US

## Our people

**Famcare**
Chair, Verena Gutmann, Austria
Susanne Blichfeldt, Denmark
Karin Clarke, South Africa
Georgina Loughnan, Australia
Yvonne Rochford, Ireland
María Elvira García Ronderos, Colombia
Karen O'Reilly, New Zealand

**Professional Providers and Caregivers Board**
Chair, Lynn Garrick, USA
Co-Chair, Laura Keane, Ireland
Patrice Carroll, USA
Larry Genstil, Israel
Neil Gumley, Australia
Norbert Hödebeck-Stuntebeck, Germany
Hubert Soyer, Germany
Mary K. Ziccardi, USA
Ex Officio: Shelly Cordner, Project Manager, IPWSO

**Our advisors**
Amalia Balart
Gary Brennan
Suzanne Cassidy
Nick Finer
Elizabeth Fistein
Joan Gardner
Jackie Gill
BJ Goff
Tony Goldstone
David Gordon
Janalee Heinemann
Engela Honey
Brian Hughes
Tomoko Iwasaki
Maria Libura
Mark Lister
James Loker
Georgina Loughnan
Esther Maina
James O'Brien
Colin Pearson
Marcello Schutzer
Molelekeng Sethuntsa
Joyce Whittington

**Our staff**
Marguerite Hughes, Chief Executive Officer
Shelly Cordner, Project Manager
Agnes Hoctor, Communication and Membership Manager
(Left January 2024)
Kate Marshall, Fundraising and Communications Manager
(Left May 2024)
Nora McNairney, Project, and Operations Manager

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## What is Prader-Willi syndrome?

Prader-Willi syndrome (PWS) is a complex genetic disorder characterised by low muscle tone and failure to thrive at birth, and later evidence of short stature, intellectual disabilities, behavioural and psychiatric challenges, and impaired satiety.

The latter is associated with excessive food intake (hyperphagia) that results in severe obesity, if access to food is not carefully controlled. Where severe obesity is a problem this can lead to additional health problems, such as type 2 diabetes mellitus and sleep apnoea.

Relative growth and sex hormone deficiencies are very common requiring hormone replacement and monitoring for other health problems is required, such as severe spinal curvature.

Research has shown that between 1 in 15,000 and 30,000 people in the populations studied are born with PWS. PWS occurs across all races and both sexes, although life-expectancy may differ between countries depending on the availability of early diagnosis, information, treatments, services and support.

## Support IPWSO

- Please donate
- Join our mailing list
- Connect with us on Facebook, Twitter, Instagram, YouTube and LinkedIn
- Attend our online and in-person events

IPWSO is registered as a charity in England and Wales, charity no. 1182873.