

www.ipwso.org



IPWSO
International
Prader-Willi Syndrome
Organisation



ANNUAL
REPORT

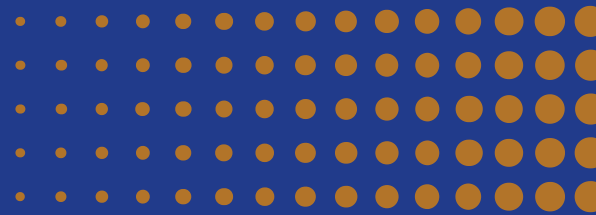
2023

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.



CONTENTS

Page

4 President's report

5 Chief Executive Officer's report

7-32 Financial Information

- Treasurer's report
- Independent Examiner's report
- Financial statements

33 Environmental Sustainability

34 Volunteers

34 Nominations Committee

35-38 Advisory boards

- Clinical and Scientific Advisory Board
- Famcare Board
- Professional Providers and Caregivers Board

39-52 Our projects

- Conferences and workshops
- International conference 2025
- Educational outreach
- Online events
- Policy and research
- People with PWS
- International advocacy
- Diagnostic testing
- Website and publications
- Advice service

53-56 About us

President's report: Prof Tony Holland

IPWSO works on a three yearly cycle with the international conferences at the beginning and end of each cycle. The 2022 Conference held in Limerick, Republic of Ireland was the stimulus for us to return to more in-person meetings, in addition to the on-going virtual meetings.

The core of our work remains ensuring that reliable diagnostic testing and sound information is available to families globally in various languages. Through our financial support for local workshops and conferences we seek to foster local expertise and ensure a better understanding of the complex needs of people with PWS. We provide a help line for families and we are there to support our members, 45 national PWS associations from across the world, as well as groups of families and professionals living and working in countries where no PWS association exists.

In 2023 we completed our Mental Health ECHO. This was part of a more extensive IPWSO mental health initiative and we will be publishing a full report on this subject in 2024. We continued our regular IPWSO Consultation meetings. These provide a forum for discussing issues of particular importance to IPWSO's work. We held our second 'Summit meeting' this one on preventing obesity and other risks, and promoting a good life for people with PWS and hosted a public meeting to inform and educate about Research and Clinical Trials. We established a Research and Clinical Trials Committee which is working to develop and define our role in this field.

Our Vice-President, François Besnier, attended the annual conference of the African Society for Paediatric and Adolescent Endocrinology (ASPAE) held in Cameroon and we also hosted booths at conferences aimed at endocrinologists, paediatricians and the rare disease community. Our Famcare Board hosted two meetings, one on mental health and behaviour and the other on the experience of siblings of children with PWS. Towards the end of 2023 we hosted a virtual meeting for families of children with PWS from the Ukraine.

The above are just some examples of the work IPWSO has undertaken during 2023. This work would not be possible without the leadership of our CEO, Marguerite Hughes, and the work of our quite exceptional staff, Agnes, Nora and Shelly. My thanks to them, to the Trustees and chairs and members of various committees, to those associations and individuals who have donated to IPWSO, to the Friends of IPWSO (USA), and to the pharmaceutical companies and other organisations who have provided financial support.

Special thanks as always to our Honorary President, Jean Phillips-Martinsson, for her continuing involvement in IPWSO and for her generosity.

We look forward in 2024 to continuing this work and developing new initiatives, to our Caregivers' Conference in Berlin, and to planning for the 2025 Conference to be held in Phoenix, Arizona. This meeting is in partnership with PWSA | USA and the Foundation for Prader-Willi Research. We say goodbye to Agnes who will be sorely missed – thank you for all the work you have done for IPWSO. Our goal remains to support people with PWS and their families and national PWS associations wherever they are in the world.



Chief Executive Officer's report: Marguerite Hughes

Working for IPWSO is never dull.

In 2023 we were once again confronted with new challenges, reasons to question how best to deploy our resources, and requests for help from families in desperate situations.

We can take pride in the volume and quality of IPWSO activities. Some were continuations of ongoing work, such as our free diagnostic testing programme for which we signed a new three-year contract with the Baschirotto Institute for Rare Diseases ensuring the continuity of this vital service. Others were new initiatives, such as our Research and Clinical Trials meeting, which attracted one of the largest attendances we have ever had for an online event.

The testimony of individuals supported by IPWSO was particularly heartening. An Eastern European mother told me that the information IPWSO had translated was the first reliable information about PWS she had ever read in her native language. I took pride in feedback from the myriad conferences and small projects that were funded by IPWSO with support from Friends of IPWSO (USA).

Pride at our achievements must be balanced against recognition of the extent of unmet need. Our membership now extends to 45 countries. Although a source of inspiration for other rare disease groups, it also means that in over three quarters of the world's countries, there is no PWS association.

Worry about whether we would raise enough money to sustain our programmes was a constant in 2023 and our elusive search for sustainable sources of funding continues. As in previous years, in 2023 IPWSO operated not primarily on money, but instead on commitment from those who believe in its mission. Most are volunteers with personal or professional knowledge of PWS and a profound drive to help people with PWS who are disadvantaged.

The commitment of our volunteers was matched by the commitment of families around the world. As one African professional told me, when governments fail, families find a way. Our member associations may be moving at different paces and in different ways but all are focused on improving the lives of people with PWS. IPWSO's role remains to support them in ways that are meaningful to their communities.

We end 2023 by saying goodbye to Agnes Hctor, our valued Communication and Membership Manager who has been instrumental in driving IPWSO's public profile and cementing our relationships with members and stakeholders around the world. We end the year too having completed a new Strategic Plan that will be published in early 2024 and underpin our work for the next three years.

I would like to thank the IPWSO Trustees, our many other volunteers, our staff, our donors and our supporters who make IPWSO's work possible.

2023 IN NUMBERS



100+ Advice line enquiries received from over **100** individuals in **47** countries

45 Members, and contacts in over **120** countries



6979 Volunteer hours

7 Conference grants awarded

6 Small project grants awarded

15 Diagnostic tests provided

409 409 people attended online meetings, from over **100** countries

4 Travel scholarships awarded

914 Hours of our videos watched on YouTube

5 Educational outreach conference visits





FINANCIAL INFORMATION

Treasurer's Report: Craig Moore

During 2023 the Finance Committee met on 10 occasions. From the outset I wish to record my thanks to Tünde Liplin, Vice Chair, who acted in my stead during the period of my absence. Tünde's knowledge, experience and support has been invaluable to me and the Finance Committee.

At the beginning of 2023 we worked on consolidating our roles given the restructuring of the Finance and Fundraising Committee with the addition of an Investment Committee and separate Fundraising Committee. This occurred due to the growing nature and complexity of our finances and our fiduciary responsibility as Trustees and staff. As Chair of the Finance Committee, I act as our link to IPWSO's Investment Committee. Our CEO, Marguerite Hughes, and Joan Gardner, who attend the Finance Committee, sit on our Fundraising Committee. In this way we can ensure that all the necessary financial information is made available to assist the Finance Committee in its deliberations and in making recommendations to the Board.

The Finance Committee also developed in 2023 a "Dashboard" Report to assist Trustees in their understanding of IPWSO Finances. This has been most useful in tracking how we have generated income, utilised our resources and measured our results against our Budget.

Together with the Investment Committee, we spent several months exploring where and how best to manage our reserves. Due to our international status, the process was complex. However, I am pleased to report that the outcome has been satisfactory as, since July 2023, we have invested a total of \$207,057 between two HSBC investment accounts. This has generated an additional \$4,528 as of 31 December 2023.

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 \$208,262 (2022: \$399,476), of which \$145,494 was restricted and \$62,768 was unrestricted. Restricted income came in the form of grants and donations from bodies within the healthcare industry, corporations and individuals. Expenditure totalled \$202,956 (2022: \$324,176), of which \$86,679 was spent from restricted funds.

There was a net surplus on restricted funds of \$36,606 which has increased brought forward funds to a total of \$74,942 (2022: \$38,336) to be carried forward. A deficit of \$31,300 on unrestricted funds, when deducted from opening funds, results in a total to be carried forward of \$337,578 (2022: \$368,878).

Our closing balance on 31 December 2023 was \$412,520 (2022: \$407,214) and we maintained the following balances in the bank accounts:

- USD 94,150
- Euro 24,390
- GBP 60,407
- GBP 6-month Money Market: £50,000
- GBP 12-month Money Market: £112,635

Income raising in 2023 has been very challenging. However, we saw an improvement in the last quarter, and we are grateful to all those companies that have committed funds to support our 2024 projects. Our Fundraising Committee is developing an income-generating strategy, and we will continue to control our costs. We are fortunate to have funds in reserve and to benefit from a variety of income sources, as detailed below.

2023 Funding Sources and Breakdown

IPWSO receives funding from the healthcare industry, donations from individuals, organisations and national associations, grants from foundations and philanthropies, membership subscriptions, and registration fees from conferences.

In 2023 IPWSO received funding from the following sources:

1. Grants from Foundations and Philanthropies
2. Donations from individuals, organisations and national associations*
3. Healthcare industry
4. Membership subscriptions from national associations
5. Investments

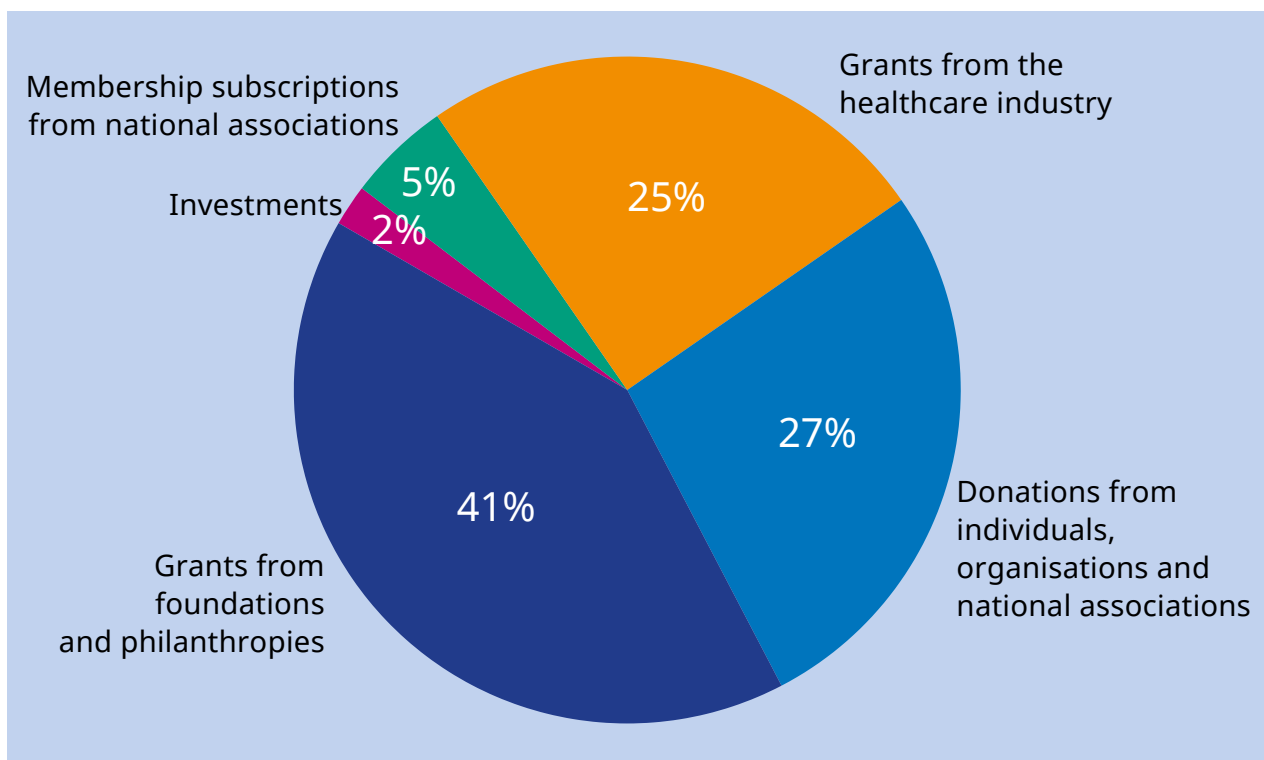
*Donations listed above included a generous donation of £25,033 from Jean Phillips-Martinsson.

The following pharmaceutical industry partners provided support to IPWSO in 2023:

Saniona
Solenio
OT4B
EPM
Aardvark
ConSynance
Gedeon Richter

The percentage of IPWSO's income provided by industry partners in 2023 was 25%. (13%* in 2022) The largest single industry donor in 2023 was Solenio Therapeutics.

* Includes indirect funding for IPWSO's 2022 conference.



How we use our funds

IPWSO supported a wide range of activities in the year from its restricted funds including diagnostic testing, grants for conference and workshops and small projects across the globe, travel scholarships for those for whom costs would be prohibitive, a profile at educational events organised by professional medical societies, online meetings on important topics such as mental health and behaviour, translation of educational materials, interpreters, the IPWSO Advice Line and the services of a professional fundraiser. Unrestricted income in the main supported staff costs, costs associated with financial reporting requirements of the Charity Commission and the virtual finance office, office running costs, engagement with other organisations, insurances, and bank charges.

The attached Financial Statements outline the income and expenditure in detail.

Acknowledgements

Sincere thanks are due to all our benefactors. Without your continuous support, commitment, and generosity, IPWSO could not fulfil its obligations to the global PWS community. We are grateful to our healthcare industry partners, member associations, and individual donors for their support. In particular, we want to thank our Honorary President, Jean Phillips-Martinsson, for her continued philanthropic support. A special mention is due also to Friends of IPWSO (USA) whose philanthropic support has been unwavering.

Thank you to Tony Holland, Marguerite Hughes and the IPWSO staff team for their leadership and dedication. I also need to highlight the contribution of Nora McNairney who has worked diligently in providing the Finance Committee reports each month and translating our ideas for a Dashboard into reality. Finally, many sincere thanks to all my colleagues on the Finance Committee, Trustees, friends, and staff, including Joan Gardner, Michelle Torbert, Tünde Liplin and Marguerite Hughes.

Major donors and sponsors

Friends of IPWSO (USA)

Jean Phillips-Martinsson

Soleno Therapeutics

Acadia Pharmaceuticals

Aardvark Therapeutics

OT4B

Gedeon Richter Plc

ConSynance Therapeutics

FRIENDS OF IPWSO (USA)

IPWSO is very 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 made possible in 2023.

Educational Outreach: Funding enabled IPWSO to support project management costs and costs for IPWSO representatives to attend educational conferences throughout 2023 with a view to raising awareness of PWS and the services IPWSO offers. This included attendance at:

- The African Society for Paediatric and Adolescent Endocrinology (ASPAE) Conference from 9–10 February 2023 in Yaoundé, Cameroon. IPWSO was also able to support attendance and travel fellowships for 4 health professionals from African countries.
- The European Society of Endocrinology's (ESE) European Congress of Endocrinology (ECE) from 13-16 May in Istanbul, Turkey.
- The 15th European Paediatric Neurology Society Congress from 20-24 June in Prague, The Czech Republic.
- The 5th MetaECHO® Global Conference from September 18-21 in Albuquerque, New Mexico.

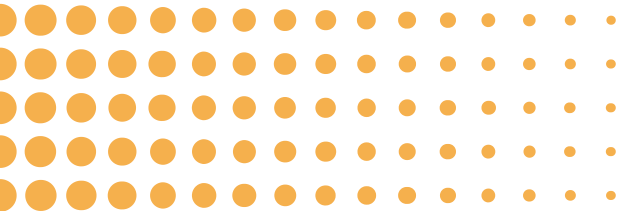
The IPWSO Mental Health ECHO®: Connects Mental Health Professionals and Professional Caregivers, to develop a community of good practice in the promotion of wellbeing and in the assessment and treatment of behaviours of concern and mental ill-health in people with PWS.

Translations: This funding enabled the production in English, Arabic, Portuguese and French of a 1-page guide for professionals on "Does your patient have PWS?". It also enabled IPWSO to support an online meeting specifically for Ukrainian families; we provided an interpreter and translated the materials from English to Ukrainian.

Support for Conferences and Workshops: Funding from Friends of IPWSO (USA) enabled IPWSO to offer support for in-person and online conferences in Colombia, Brazil, India, South Africa, Romania, China and Egypt.

Support for Small Projects: This funding enabled the Argentinian, Hungarian and Thai PWS Associations to hold meetings for people with PWS and their families. It enabled the Egyptian PWS group to formally establish their association. The Aster CMI Hospital in Bengaluru, India, received funding to develop specific patient education material on PWS in 4 local Indian languages and also in English, and academics from the Taylor’s University in Malaysia set up a support group programme for parents of people with PWS.

CRM system: Support to host a Customer Relationship Management system (CRM) to keep track of IPWSO’s contacts and to manage and record interactions.



INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2023

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 2024 and onwards include preparation for the 6th International Prader-Willi Syndrome Caregivers' Conference in Berlin from 21-23 May 2024 and the United in Hope: International PWS Conference to be held from 24-28 June 2025 at the Arizona Grand Resort and Spa in Phoenix, Arizona, USA, in partnership with PWSA | USA and FPWR. IPWSO envisages that this unique collaboration will serve as a catalyst for the largest international PWS conference ever held.

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.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 DECEMBER 2023**

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: 18 March 2024

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 31 DECEMBER 2023**

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 2023.

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

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.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**INDEPENDENT EXAMINER'S REPORT (CONTINUED)
FOR THE YEAR ENDED 31 DECEMBER 2023**

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: 25 March 2024

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

Chartered Accountants

Cambridge

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 DECEMBER 2023**

	Note	Restricted funds 2023 \$	Unrestricted funds 2023 \$	Total funds 2023 \$	Total funds 2022 \$
INCOME FROM:					
Donations	2	140,029	42,988	183,017	178,426
Charitable activities	3	5,465	15,252	20,717	221,050
Investments	4	-	4,528	4,528	-
TOTAL INCOME		145,494	62,768	208,262	399,476
EXPENDITURE ON:					
Charitable activities	5	86,679	116,277	202,956	324,176
TOTAL EXPENDITURE		86,679	116,277	202,956	324,176
NET INCOME/(EXPENDITURE)		58,815	(53,509)	5,306	75,300
Transfers between funds	12	(22,209)	22,209	-	-
NET MOVEMENT IN FUNDS		36,606	(31,300)	5,306	75,300
RECONCILIATION OF FUNDS:					
Total funds brought forward		38,336	368,878	407,214	331,914
Net movement in funds		36,606	(31,300)	5,306	75,300
TOTAL FUNDS CARRIED FORWARD		74,942	337,578	412,520	407,214

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

The notes on pages 11 to 23 form part of these financial statements.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**BALANCE SHEET
AS AT 31 DECEMBER 2023**

	Note	2023 \$	2022 \$
CURRENT ASSETS			
Debtors	9	17,776	654
Investments	10	207,057	-
Cash at bank and in hand		197,986	411,626
		422,819	412,280
Creditors: amounts falling due within one year	11	(10,299)	(5,066)
		412,520	407,214
NET CURRENT ASSETS		412,520	407,214
TOTAL NET ASSETS		412,520	407,214
CHARITY FUNDS			
Restricted funds	12	74,942	38,336
Unrestricted funds	12	337,578	368,878
TOTAL FUNDS		412,520	407,214

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

Craig Moore

.....
Craig Moore
Treasurer

Date: 18 March 2024

The notes on pages 11 to 23 form part of these financial statements.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023**

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.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023**

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.

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.

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.

All expenditure is inclusive of irrecoverable VAT.

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.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023**

1. ACCOUNTING POLICIES (CONTINUED)

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 2023**

2. INCOME FROM DONATIONS

	Restricted funds 2023 \$	Unrestricted funds 2023 \$	Total funds 2023 \$	Total funds 2022 \$
Donations	53,381	42,988	96,369	178,426
Grants	86,648	-	86,648	-
TOTAL 2023	<u>140,029</u>	<u>42,988</u>	<u>183,017</u>	<u>178,426</u>
TOTAL 2022	<u>136,951</u>	<u>41,475</u>	<u>178,426</u>	

3. INCOME FROM CHARITABLE ACTIVITIES

	Restricted funds 2023 \$	Unrestricted funds 2023 \$	Total funds 2023 \$	Total funds 2022 \$
Member subscriptions	-	10,252	10,252	10,139
Grants	-	-	-	38,926
Diagnostic testing	5,465	-	5,465	3,565
PWSA USA Association (ECHO project)	-	5,000	5,000	-
Conference income	-	-	-	168,420
TOTAL 2023	<u>5,465</u>	<u>15,252</u>	<u>20,717</u>	<u>221,050</u>
TOTAL 2022	<u>210,911</u>	<u>10,139</u>	<u>221,050</u>	

4. INVESTMENT INCOME

	Unrestricted funds 2023 \$	Total funds 2023 \$	Total funds 2022 \$
Money market interest	<u>4,528</u>	<u>4,528</u>	<u>-</u>

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023**

5. ANALYSIS OF EXPENDITURE BY ACTIVITIES

	Activities undertaken directly 2023 \$	Support costs 2023 \$	Total funds 2023 \$	Total funds 2022 \$
Charitable expenditure	181,872	21,084	202,956	324,176
	<u>181,872</u>	<u>21,084</u>	<u>202,956</u>	
TOTAL 2022	277,695	46,481	324,176	
	<u>277,695</u>	<u>46,481</u>	<u>324,176</u>	

ANALYSIS OF DIRECT COSTS

	Total funds 2023 \$	Total funds 2022 \$
Staff costs	119,130	110,151
ECHO project	-	2,878
Conferences and events costs	52,073	142,535
Diagnostic testing	7,261	2,922
Website costs	2,332	906
Clinical Trial Consortium	-	1,000
Translations	1,076	17,303
	<u>181,872</u>	<u>277,695</u>

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023**

5. ANALYSIS OF EXPENDITURE BY ACTIVITIES (CONTINUED)

ANALYSIS OF SUPPORT COSTS

	Total funds 2023 \$	Total funds 2022 \$
Accountancy and bookkeeping fees	10,462	10,514
Foreign currency exchange	(7,821)	15,141
Advertising and marketing	200	591
Insurance	1,512	1,386
IT software and consumables	1,866	1,362
Bank charges	968	1,010
Miscellaneous expenses	1,163	6,615
Office running costs	4,949	9,862
Professional and consultancy fees	7,785	-
	21,084	46,481

6. INDEPENDENT EXAMINER'S REMUNERATION

	2023 \$	2022 \$
Fees payable to the CIO's independent examiner for the independent examination of the CIO's annual accounts	1,908	1,645
Fees payable to the CIO's independent examiner in respect of:		
Preparation of statutory financial statements	2,723	2,348
Bookkeeping services	4,483	5,414

7. STAFF COSTS AND KEY MANAGEMENT PERSONNEL

	2023 \$	2022 \$
Wages and salaries	113,233	106,627
Social security costs	3,746	1,532
Contribution to defined contribution pension schemes	2,151	1,992
	119,130	110,151

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023**

7. STAFF COSTS AND KEY MANAGEMENT PERSONNEL (CONTINUED)

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

	2023	2022
	No.	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 \$19,860 (2022: \$18,678).

8. TRUSTEES' REMUNERATION AND EXPENSES

During the year, no Trustees received any remuneration or other benefits (2022 - \$NIL).

During the year ended 31 December 2023, expenses totalling \$5,072 were reimbursed or paid directly to 3 Trustees (2022 - \$2,964 to 4 Trustees). These expenses related to travel, accommodation and subsistence.

9. DEBTORS

	2023	2022
	\$	\$
Trade debtors	17,776	-
Other debtors	-	654
	17,776	654

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023**

10. CURRENT ASSET INVESTMENTS

	2023	2022
	\$	\$
1-year money market investments	207,057	-

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023	2022
	\$	\$
Trade creditors	4,757	548
Other taxation and social security	296	-
Other creditors	453	525
Accruals and deferred income	4,793	3,993
	10,299	5,066

	2023	2022
	\$	\$
Deferred income at 1 January 2023	-	66,329
Resources deferred during the year	163	-
Amounts released from previous periods	-	(66,329)
	163	-

Deferred income represents 2024 membership fees received in advance.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023**

12. STATEMENT OF FUNDS

STATEMENT OF FUNDS - CURRENT 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
Caregivers Conference	-	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	-	-	-	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>
TOTAL OF FUNDS	<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>

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023**

12. STATEMENT OF FUNDS (CONTINUED)

STATEMENT OF FUNDS - PRIOR YEAR

	Balance at 1 January 2022 \$	Income \$	Expenditure \$	Transfers in/out \$	Balance at 31 December 2022 \$
UNRESTRICTED FUNDS					
General Funds	244,819	51,614	(113,875)	186,320	368,878
RESTRICTED FUNDS					
IPWSO					
Conference/MeetingFund	49,483	304,134	(128,534)	(225,083)	-
Diagnostic testing	5,693	3,391	(3,005)	-	6,079
Digital Lift Grant	-	174	(180)	6	-
ECHO Funding	19,329	-	(33,236)	13,907	-
Friends: CRM System	-	13,668	(11,415)	-	2,253
Frends: Mandarin Translations	-	2,959	(2,760)	(199)	-
Friends: Pakistan Conference	-	7,380	-	-	7,380
Friends: Travel Grants	-	1,927	(6,244)	4,317	-
Global Genes	-	14,229	(14,851)	622	-
Friends: meetings and workshops	-	-	-	20,270	20,270
Raising Awareness	2,354	-	-	-	2,354
Mental Health Workshop	10,236	-	(10,076)	(160)	-
	<u>87,095</u>	<u>347,862</u>	<u>(210,301)</u>	<u>(186,320)</u>	<u>38,336</u>
TOTAL OF FUNDS	<u><u>331,914</u></u>	<u><u>399,476</u></u>	<u><u>(324,176)</u></u>	<u><u>-</u></u>	<u><u>407,214</u></u>

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023**

12. 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.

Conference/Meeting - this fund represents monies received from Friends of IPWSO (USA) to support PWS conferences and workshops around the world.

Diagnostic Testing - this fund represents monies received from OT4B and also from fundraising campaigns and is used to support diagnostic testing for Prader-Willi syndrome.

6th International PWS Caregivers' Conference 2024, Berlin - this fund represents income to support a conference and also delegate attendance, for those who could not otherwise afford to travel. Funds have been received from the healthcare sector, professional caregiving organisations and also Friends of IPWSO (USA).

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 fund 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.

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

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.

Educational Outreach - this fund represents monies received from Friends of IPWSO (USA) and also from the healthcare industry to support IPWSO's presence at PWS related international conferences and also to support travel and accommodation for delegates who could not otherwise afford to attend.

Friends Travel scholarship (ASPAE) – this fund represents monies for travel scholarships for delegate attendance at the 14th Congress of the African Society of Paediatric and Adolescent Endocrinology (ASPAE) in Cameroon.

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

Friends: travel scholarship PCC - funds for travel scholarships for delegate attendance at the 14th Congress of the African Society of Paediatric and Adolescent Endocrinology (ASPAE) in Cameroon.

Friends 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.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023**

12. STATEMENT OF FUNDS (CONTINUED)

Friends: filming PPC 2024 conference: this fund represents monies received from Friends of IPWSO (USA) for the filming of the PPC 2024 conference.

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

Global Genes - funding towards the implementation of a programme to support and improve outreach strategies and address challenges that affect underserved and underrepresented patient communities.

Digital Lift grant - funding to help IPWSO advance its technology.

Travel grants - funding towards travel to the 11th conference.

Mandarin translations - funding towards translation of IPWSO documents into Mandarin.

Mental Health Workshop - Funds received from Friends of IPWSO USA in support of IPWSO's mental health network including an event held in 2022.

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.

13. ANALYSIS OF NET ASSETS BETWEEN FUNDS

ANALYSIS OF NET ASSETS BETWEEN FUNDS - CURRENT YEAR

	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	<u>74,942</u>	<u>337,578</u>	<u>412,520</u>

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023**

13. ANALYSIS OF NET ASSETS BETWEEN FUNDS (CONTINUED)

ANALYSIS OF NET ASSETS BETWEEN FUNDS - PRIOR YEAR

	As restated Restricted funds 2022 \$	As restated Unrestricted funds 2022 \$	As restated Total funds 2022 \$
Current assets	38,336	373,944	412,280
Creditors due within one year	-	(5,066)	(5,066)
TOTAL	<u>38,336</u>	<u>368,878</u>	<u>407,214</u>

14. PENSION COMMITMENTS

The CIO operates a defined contribution pension scheme. The assets of the scheme are held separately from those of the group in an independently administered fund. The pension cost charge represents contributions payable by the CIO to the fund and amounted to \$2,151 (2022 - \$1,992). \$453 (2022 - \$403) were payable to the fund at the balance sheet date and are included in creditors.

15. 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 6,979 hours compared with 4,950 hours by staff.

16. RELATED PARTY TRANSACTIONS

During the year, donations totalling \$11,990 were received from 7 trustees. There are no conditions attached to these donations.

ENVIRONMENTAL SUSTAINABILITY

In late 2022 IPWSO applied to the London School of Economics (LSE) Community Engagement Programme for a team of student volunteers who could research the environmental impact of our work. This team led a consultation in early 2023 with IPWSO stakeholders from around the world seeking feedback on how IPWSO could reduce its environmental impact.

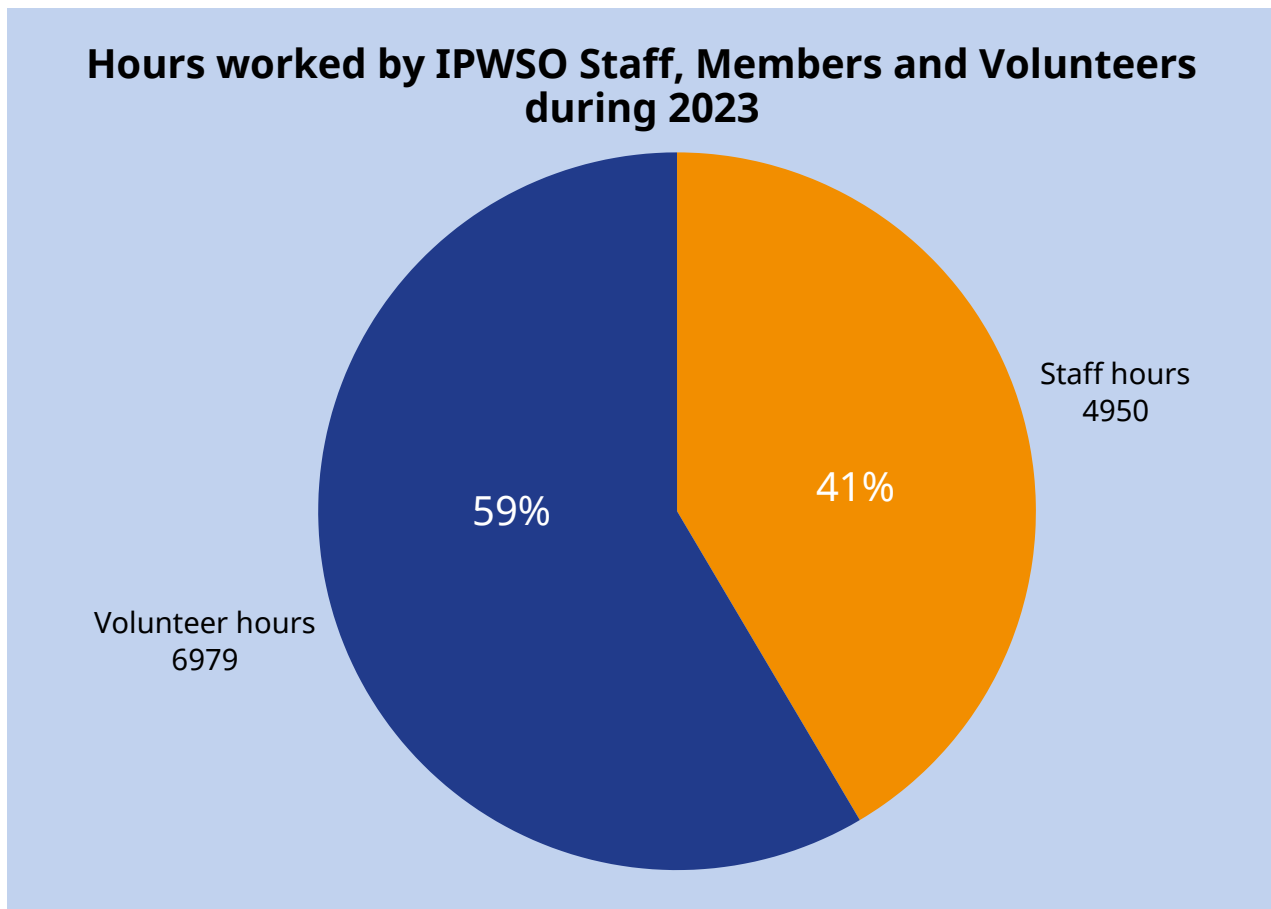
Following consideration of the LSE students' recommendations, the IPWSO Board committed in May 2023 to:

- Take environmental impact into consideration when allocating grants;
- Take environmental impact into consideration when selecting the fora at which IPWSO raises awareness of PWS;
- Various actions aimed at reducing the environmental impact of IPWSO's triennial conferences;
- Seek a free and simple means of calculating IPWSO's overall carbon emissions so that we can monitor and aim to reduce emissions over time;
- As a priority, review our digital emissions and seek means of achieving reductions;
- Comment on IPWSO's environmental impact and actions to reduce emissions in future annual reports and on our website;
- Ask suppliers and service providers about their environmental policies where we feel this is appropriate;
- Sign up to the Climate and Environmental Leadership Principles formulated by the Association of Chief Executives of Voluntary Organisations (ACEVO) in the UK and utilise them as a framework to support our progress.

While IPWSO does not have an environmental remit, we accept that we all have a responsibility in relation to the environmental crisis and will continue to make changes to reduce the negative environmental impact of our work where we can.

VOLUNTEERS

The hours committed by volunteers far outstrip the number of hours worked by paid staff.



NOMINATIONS COMMITTEE

IPWSO's new Nominations Committee convened for the first time in July chaired by our legal advisor, Colin Pearson. Its brief is to prepare a slate of recommended candidates for the positions of IPWSO President and Trustees for consideration by the Board of Trustees prior to the General Assembly in 2025. More information about the vacant positions can be obtained by emailing office@ipwso.org.



ADVISORY BOARDS

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

Membership of CSAB:

The membership of the CSAB consists of 16 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.

Scientific papers:

The CSAB has continued to prepare listings of 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, and 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 collections of papers are available on our website.

Advice:

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

IPWSO 2025 meeting in Phoenix, USA:

The CSAB is preparing to run another successful International Clinical and Scientific (C&S) meeting in Phoenix, USA in June 2025. The IPWSO meeting will be a partnership with PWSA | USA and FPWR. The IPWSO C&S meeting is the premier and best attended international clinical and scientific meeting in the world for PWS. We anticipate that the 2025 meeting will be the most robust and best attended C&S meeting to date given the partnership among the three PWS patient advocacy groups involved (IPWSO, PWSA | USA, and FPWR).

Famcare Board: Verena Gutmann

In 2023 the Famcare Board met regularly and discussed a range of issues and challenges affecting people with PWS and their families. Many thanks to our wonderful Board members for their commitment and input. We were very sad to say farewell to Lesley Robertson this year. She has been a member of Famcare since the very beginning and Famcare and IPWSO have greatly benefited from her wisdom and expertise – thank you Lesley and best wishes for the future!

This year we worked on the publication of two new guides which we hope will be useful for families:

- After the Diagnosis, Relief and Acceptance: this guide looks at the importance of diagnosis in our journey as parents of a child with a rare disease. Diagnosis may come very early in our child's life, or for some families it happens much later on, after a long battle for recognition. Whenever the diagnosis occurs, it is a shock and a huge challenge for us as parents. Diagnosis is vital though; it is the key that unlocks the information we need about how to support our child and how to access the care and treatment they need. It also helps us connect and identify with other families in the same position, both in our own country and in the IPWSO global community where we find we have so much in common.
- Preparing for the future: When parents die: thinking about the future is one of our responsibilities as parents. Preparing our child to live independently from us will involve many considerations around where they live, their care, financial and legal matters and responsibilities for decision-making. Many of these issues will differ significantly from country to country. In this guide we outline some of the key items to think about. We hope it will act as a useful nudge to tackle what may often be a difficult and uncomfortable issue to discuss within your family.

We were also delighted to host two webinars this year for families, siblings and other people involved in the care of people with PWS. Presentations from both events are available on our website and YouTube channel:

- Managing challenging behaviour in PWS: managing behaviour is one of the key challenges that parents contact IPWSO about. We wanted to host a webinar for a chance to hear from some of our experts about the most common issues that arise, as well as to discuss some real-life stories.
- Siblings: siblings of people with PWS face some unique challenges, their lives will be different to those of their peers at school and their family responsibilities and relationships are also likely to be affected. In this moving and illuminating meeting we heard from siblings about their lives and relationships and some of the highs and lows that they have experienced.

We look forward to continuing to meet in 2024 to continue to face the challenges of the syndrome and find ways to support each other in our global community. We will also be looking to our next IPWSO International Conference in 2025.



Professional Providers and Caregivers Board: Lynn Garrick

2023 began with conference planning for the 6th International Caregivers' Conference. The caregiver's conference has continued to be a highly anticipated gathering of providers globally since the first International Caregivers' Conference in Herne, Germany, in 2008. Despite needing to change the original location from Israel, the PPCB is thrilled to be able to hold the 2024 caregivers conference in Berlin, Germany, on May 21-23, 2024.

The Caregivers' Conferences allow for the personal exchange of best practices, visions for the future, and collaboration with global caregivers. PWS caregiving remains critical to the overall well-being of a person with PWS. We are delighted to be able to put on a conference that is dedicated to all things caregiving and know that together, we can collaborate to enable new and constructive thoughts and approaches while learning from each other's knowledge and experiences.

Our board members continue to work with the mental health network to provide ongoing education and support relating to the mental health issues that surround individuals with PWS. This initiative aims to develop a community of good practices in promoting well-being and assessing and treating behaviours of concern.

The board continues to find ways to attract and work alongside caregiver delegates who collaborate with the board to deliver information to local caregivers. One of the many benefits of having caregiver delegates is that it forms and continues partnerships at a local level to maintain an awareness of the work of IPWSO while allowing for feedback on specific areas that may need further education, research, or guidance.

The PPCB aims to provide the people who directly support people with PWS with the most qualified tools and to offer them for use throughout the world. This would not be possible without the steadfast dedication of the members of the PPCB. It remains my continued honour to work with the current PPCB members: Patrice Carroll, Larry Genstil, Neil Gumley, Norbert Hödebeck-Stuntebeck, Laura Keane, Hubert Soyer, and Mary K. Ziccardi, ably assisted by Shelly Cordner from the IPWSO Office.



OUR PROJECTS



Conferences and Workshops Grant Awards: Lynn Garrick

The Grants Committee, thanks to the generous support of Friends of IPWSO (USA), was pleased to offer grants totalling \$32,180 for seven conferences held in 2023 or to be held in early 2024. It is our pleasure to share with you some of this amazing work and its impact for our global PWS community.

Romania: The Prader-Willi Association in Romania together with the National Alliance for Rare Diseases in Romania held an international conference from 30-31 May in Timisoara on the theme of "Behaviour Management in PWS". Eighty-three people participated and there were sessions for children and adults with PWS. The wide range of speakers included Dr Susanne Blichfeldt, Hubert Soyer and Norbert Hödebeck-Stuntebeck.

Colombia: The Asociación Colombiana Síndrome de Prader-Willi held their 3rd International Symposium from 27-29 July in Bogota on the theme of "Transforming Lives For A Better Future". This online and in-person event attracted an amazing 1,553 delegates from 40 countries and included programmes for scientists and clinicians, families, and people with PWS. Again, there was a wide range of international speakers online and in-person including Tony Holland, Jorgelina Stegmann, Larry Genstil, Linda Gourash, Janet Forster and Norbert Hödebeck-Stuntebeck.

China: The first Academic Exchange Conference for Experts on Prader-Willi Syndrome was successfully held in Hangzhou on 6 July. This was for primary-level doctors and the meeting attracted more than 100 medical professionals. The good attendance highlighted the strong willingness of grassroots doctors from all over the country to improve their professional knowledge and skills related to rare diseases including PWS. On behalf of the Prader-Willi expert group of Zhejiang Children's Hospital, Professor Zou Chaochun, the chairman, gave a report on the latest progress in the diagnosis and treatment of PWS and the clinical research undertaken in recent years. Participants shared their experience and insights and Professor Chaochun said the doctors had absorbed a wealth of knowledge and experience through the expert reports delivered at the conference, and further improved their knowledge and understanding about the diagnosis and treatment of PWS.

Brazil: The 1st SPW Brasil Symposium took place in Rio de Janeiro on 28 October with the theme "A New Look at Prader-Willi Syndrome". The event brought together around 150 people for a full day of lectures and networking. The team of speakers included Dr Janice Forster and Patrice Carroll, as well as Brazilian doctors specializing in the areas of genetics, endocrinology, and sleep medicine. The topics covered had one thing in common, behavioral disorders. To showcase their work, SPW Brasil produced a video (available on their website), which provides an excellent insight to their very successful inaugural event. Liane Motta, President of SPW Brasil said, "Our social networks were filled with comments praising this very important initiative for the Prader-Willi community in Brazil. Thank you IPWSO and Friends of IPWSO (USA) very much again for your support!"

South Africa: Prader-Willi Support (South Africa) held workshops in-person in Pretoria and Cape Town as well as live online on 18 November, attracting over 55 delegates. Speakers and topics included Dr Engela Honey - Medical care in South Africa, Dr Steve Delport - Endocrine issues and care in South Africa, Kath Megaw - Nutrition for PWS and Janice Forster - Behaviour management and mental health. A Geneticist at Red Cross War Memorial Hospital in Cape Town who attended the event found the talk by Janice Forster so helpful that she is showing the video to her whole department and all the genetic counsellors and students. Karin Clarke, Chairperson PWS Support Group, commented on the need for these networking events in South Africa in order to dispel myths around Growth Hormone Treatment and to arm parents with knowledge about standards of care they should request from their doctors.

India: The Paediatric Endocrine team at Aster Hospital in collaboration with the Indian Prader-Willi Syndrome Association held a hybrid Scientific and Family Conference on 16 December in Bengaluru, India. There were many notable speakers including orthopaedic expert Dr Harold van Bosse.


The Grants Committee is grateful to Friends of IPWSO (USA) for enabling these activities and to all those speakers who have given freely of their time and expertise. We look forward to supporting other countries that will be hosting virtual or in-person conferences in 2024.

Small Projects Grant Awards: Lynn Garrick


In a new initiative in 2023, IPWSO, thanks to Friends of IPWSO (USA), offered small grant opportunities to support the efforts of individuals and groups who are working to improve the lives of people with PWS. Awards were offered up to US\$2,000 per project and there were no restrictions on the types of projects that would be considered for funding, other than the expectation that projects were of benefit to more than one family, were concerned with building the capacity of networks or individuals to support people with PWS or involved activities that are expected to directly assist people with PWS and their families.

Egypt: In a dream come true for Walaa Mohamed, mom to Ahmed aged 13 who has PWS, the PWS Association in Egypt and Middle East (PWSA EG-ME) was officially founded on 1 June. The Association will serve the entire Arab and Middle East region. IPWSO's small grants scheme has helped finance the official incorporation of the Association and now individuals and families affected by PWS in this region have an established community to find help, support, and hope.

Hungary: The PWS Association in Hungary used their grant to organise their first Family Summer Camp which was held in Patca, Hungary, from 4-7 August. There were 36 participants and a variety of activities for the children with educational sessions for parents and guardians. Summing up their thoughts after the event, one parent said,



The greatest benefit of the camp is the quality time spent with our children, where they feel themselves - secure, where they are normal and equal, like others. Other people didn't handle them like strangers. Unfortunately, these are rare moments in everyday life. Easier for children to accept themselves; they are not different here. Thank you very much for organizing the event.



Argentina: Fundación SPINE held a Winter Camp from 17-28 July in Buenos Aires. The programme provided social and physical activities for 15 people with PWS and was facilitated by physio and occupational therapists. This is an annual project and SPINE used their funds to purchase new sports equipment.

Malaysia: Academics from the school of Liberal Arts Science at Taylor's University teamed up with the national PWS Association in Malaysia to deliver an educational programme focussed on supporting parents to address the challenges of transition through the teenage years; parents worked on developing the tools that can assist them and their loved one with PWS to navigate these challenging years. The initiative provides an excellent example of the benefits of collaboration and the group worked to produce an excellent resource for parents entitled "Caring for Prader-Willi Syndrome in Malaysia: Essential tips for parents".

India: Dr Jahnavi Muralikrishnan, Fellow in Paediatric Endocrinology, and her team at Aster CMI Hospital, were awarded funding to develop and translate educational materials into 4 local Indian languages. Dr Jahnavi reported that there is a lack of country specific PWS patient education materials. Parents who can read English can download materials from PWS websites, however, non-English speakers are distinctly disadvantaged. Additionally, a considerable amount of guidance that is available is not relevant to the way people of India live and eat. The Indian-specific patient educational booklet entitled "Understanding Prader-Willi syndrome - A Guide for Parents and Caregivers" was unveiled at a conference held in Bangalore in December 2023 and will be included on the Indian Prader-Willi Syndrome Association's website.

Thailand: In December PWS Thailand held their one-day annual meeting attracting 24 families. The association used their funding to help support delegate attendance and to translate much needed PWS educational materials from English to Thai.

Very many thanks to my colleagues, Susanne Blichfeldt, Norbert Hödebeck-Stuntebeck, Svetlana Laburn, Georgina Loughnan and Nora McNairney for all their support throughout 2023.

2025 International PWS Conference



Our 12th International Prader-Willi Syndrome Organisation Conference will be held at the Arizona Grand Resort and Spa, Phoenix, Arizona, USA, from 24 – 28 June 2025. The event will be hosted by PWSA | USA, the Foundation for Prader-Willi Research (FPWR) and IPWSO. Our theme "United in Hope" reflects this unique collaboration, which we expect will result in the largest international PWS conference ever held. Please hold the dates firmly in your diary and we will look forward to keeping you up to date with developments in 2024.

Educational Outreach

The **14th African Society for Paediatric and Adolescent Endocrinology (ASPAE) Conference** took place from 9–10 February in Yaoundé, Cameroon with the theme, “Diabetes and Endocrine Diseases in African Children: The Continuum of Care from Neonate to Adulthood in the Era of Technological Innovation”.

Thanks to the grant from Friends of IPWSO (USA), we were listed as a sponsor on the conference website and materials, and our French-speaking Vice-President, François Besnier, who for many years has been in contact with West African professionals, represented IPWSO and hosted the information table. François made contact with around 70 medical professionals who came from Cameroon, Tunisia, Senegal, Côte d'Ivoire, Czechia, and Luxembourg. François also presented at a roundtable event on “IPWSO and PWS”. Delegates included students, health managers, endocrinologists, paediatricians, neonatologists, epidemiologists, and psychiatrists. Overall, there were 450 delegates at the congress.

Following François’ discussions with delegates, the need for a simple one-page communication to help professionals diagnose PWS was identified. This has now been produced and is being distributed at educational events, to rare disease groups and to our newly identified African contacts.

François reported that the congress was a very good opportunity to promote IPWSO and raise awareness of PWS in Africa. He had many visitors to our information table over the two days and identified five possible professional delegates for IPWSO one from each of these countries - Côte d'Ivoire, Senegal, Cameroon, Tunisia, and Algeria; they have all accepted the invitation. Moreover, François made contact with Pr. Asmabane Ladjouze who will organise next year’s ASPAE congress in Algiers. IPWSO’s presence would be welcomed. Alain Binyet, a contact in Africa, helped François host our information table. Alain is keen to set up a central Africa network open to all rare diseases. François continues to explore ways to develop our network.

The Friends of IPWSO (USA) grant enabled us to provide support for travel and free registrations to 4 African delegates:

- Sagna Yempabou, Masters Student in Paediatric Endocrinology, Burkina Faso,
- Sandrine Laure Ngambono, Paediatrician, Faculty of Medicine, and Biomedical Sciences, Yaounde, Cameroon,
- Naiza N Monono, Senior Lecturer, Faculty of Health Sciences, University of Buea, Cameroon, and
- Ntsoli Gaelle, Paediatrician, Laquintinie Hospital, Cameroon.

IPWSO’s support at ASPAE was mentioned several times over the two days and our attendance has helped us consolidate our reach into Africa and to develop new audiences.

The European Society of Endocrinology's (ESE) **European Congress of Endocrinology (ECE)** took place from 13-16 May in Istanbul, Turkey. IPWSO hosted an information table and was represented by IPWSO advisers, Constanze Lämmer and Charlotte Höybye, and also our Communications and Membership Manager, Agnes Hoctor.

IPWSO's information table was situated within a small patient advocacy zone at the conference. Over 70 USBs drives containing information and guidance plus several copies of articles and guidance were distributed. Our representatives had conversations with 45 visitors from over 20 countries, which included several from countries where we have had little contact before now, including Nepal, Iran, and Iraq; we noted that the doctor from Iraq has several patients with PWS.

IPWSO also hosted a 30-minute presentation with a Q&A at the hub session at 8am on Monday 15 May. We were pleased to join other patient advocacy groups for a meeting with the new president of ESE and we also joined ESE colleagues and other delegates to share social media resources about European Hormone Day which took place during the event.

The **15th EPNS Congress** took place from 20-24 June in Prague, Czechia. The target audience for the Congress was Paediatric Neurologists, Neuro-disability Specialists, Neurophysiologists, Patient Advocacy Group Representatives, Child Psychiatrists, Geneticists, Adult Neurologists, Nurse Specialists, Neuropsychologists, Speech and Language Therapists, Industry Partners and Neuroscientists.

Tünde Liplin, PWS Hungary, and Hana Verichová, PWS Czechia, represented IPWSO. Twenty-two people from countries including Georgia, Israel, Lithuania, Turkey, Italy, Slovakia, Romania, Netherlands, Bosnia Herzegovina, Belgium, Argentina, Norway, Serbia, India, and Australia subscribed to the "Stay in touch with IPWSO!" contact list. Tünde reported that many people came to the stand just to inquire and chat, the majority of whom had never heard of IPWSO. A Belgian doctor mentioned that they want to establish a PWS health centre in their country and that she would welcome connecting with a country that already has this service. IPWSO has facilitated this link. On the first evening, Tünde spoke with an Italian doctor, who was very happy to hear parents' experiences about PWS.

We were also able to advise the Argentinian, Romanian and Indian doctors that there are national organisations in their counties that are members of IPWSO.

The **5th MetaECHO® Global Conference** took place from 18-21 September in Albuquerque, New Mexico, USA. It celebrated 20 years of ECHO© programmes and brought together ECHO leaders, partner teams, government officials, funders, policy makers, and industry experts to share retrospective work and thoughts on the future of ECHO.

IPWSO's President, Tony Holland, presented a paper on "A Global ECHO Programme for the Rare Disorder – PWS", based on IPWSO's Project ECHO programme in a session devoted to rare disorders. The discussion during the session involving two other rare disorder organisations highlighted the particular challenges with rare disorders, such as identifying key contacts in countries and then maintaining participation throughout the ECHO programme. Highlights of the general programme included presentations from WHO officials and presentations and discussions about what makes ECHO programmes different.

There were opportunities for informal networking and this led to meeting different disciplines engaged in ECHO programmes across the world and establishing a medical contact in Namibia and also links with a researcher from the London School of Economics who specialises in the design of health systems with special reference to Africa. He has worked with another rare disease organisation and is interested in engaging with IPWSO. It was clear that the ECHO movement is now extremely well established globally and is expanding beyond health into, for example, education, and criminal justice. New developments with the iECHO data collection system were demonstrated – as yet not available to an organisation registered in Europe for data protection reasons – but once available it will enable IPWSO to have a much more in-depth understanding of attendance etc at our ECHO programmes.

IPWSO hosted a booth at the **Cambridge RARE Conference** in Cambridge, UK on 12 October. Tony Holland and Agnes Hoctor both attended to take part in the opportunities for networking and discussion with other stakeholders in the rare disease community.

Online events: Karin Clarke and Shelly Corder

In 2023 we continued to build IPWSO's capacity to connect the global PWS community virtually by expanding our programme of online events. Over the year 409 individuals attended our Zoom meetings, and we connected with people from over 100 countries.


Since 2020, IPWSO has run ECHO® programmes, based on a tele-mentoring model designed by the ECHO Institute in the University of New Mexico. From March 2023 we ran the **IPWSO Mental Health ECHO**, aimed primarily at Mental Health Professionals and Professional Caregivers. Sessions covered 6 topics, including; Wellbeing and quality of life; Early intervention for children with PWS; and Behaviours of concern.

In 2022, we began holding annual Summit Meetings, providing an international online forum at which key issues of relevance to people with PWS and their families, and our international community, are discussed. In May 2023 we held a Summit on **Preventing obesity and other risks, and promoting a good life**, where we explored global experiences of restrictions and supporting independence.

This year, our Famcare Board introduced Family Meetings, virtual information sessions on topics relevant to families of people with PWS. We were pleased to host **Managing challenging behaviour in PWS**, in April, and **Having a brother or sister with PWS**, in November. We connected with many families to invite discussion, offer hope and support, and sought to empower families to manage challenges.


Also new to our online events calendar in 2023 was our **Research and Clinical Trials update meeting**, in September. We were delighted to welcome speakers delivering 8 presentations on the clinical trials process and information on current, planned, and recently concluded trials for PWS.

For those unable to attend meetings online, we record most virtual presentations to share with our wider audience. In recent years IPWSO has increased the number of videos on PWS available on our YouTube channel, (from 14 videos uploaded between 2015-2020, to 178 uploaded since Jan 2021) and we continue to grow this resource.



The IPWSO online meetings are so important. It can feel very isolated as a parent of a child with PWS, even in a country with good medical care for PWS sufferers. The IPWSO meetings are so good to hear best practice examples from all over the world. Please do continue, the connections are essential. Many thanks for all of your excellent efforts.

Our thanks to all those subject experts who gave presentations, and to Patrice Carroll, Tony Holland, and Kate Woodcock for their support as members of the Online Events Committee.



Policy and research: Prof Tony Holland

Research and Clinical Trials Committee: During 2023 IPWSO established this new Committee. The purpose of the Committee was initially to explore whether or not IPWSO should engage more fully in research and clinical trials, and, if so, to establish our main priorities. Following a period of consultation, we advised the IPWSO Board of Trustees that there were gaps in PWS research and IPWSO was in a strong position to fill such gaps in partnership with our membership and with the Foundation for Prader-Willi Research (FPWR) amongst others. The Trustees approved the proposed Research Strategy and the Terms of Reference for the Committee and a timetable of activities has been established.

This new initiative was in recognition of the advances that are being made in our understanding of PWS and particularly the fact that there had been and continued to be Phase 2 and Phase 3 treatment trials being undertaken. It was recognised that these trials were primarily limited to North America and Europe and new treatments, when they become available, may not have a global reach. In addition, there is very limited research on issues that might be particularly relevant to less well-off countries where families may be struggling to receive a diagnosis and the basics of intervention.

This new Committee therefore aims 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 in clinical trials. One example of research that was undertaken by IPWSO was led by Brian Hughes and has investigated the impact of PWS specialist support in the health and wellbeing of people with PWS.

Residential study: With support from providers of specialist care services around the world, Brian Hughes led an IPWSO research project that examined body weight, behavioural well-being, and social contact in persons with PWS who enter full-time specialist care services. These results have been submitted for publication.

Research and Clinical Trials Update Meeting: On 7 September we hosted the inaugural meeting of what we hope will become an annual event. The meeting set out to explain the relevance of clinical trials to the lives of people with PWS and to present an opportunity to hear about current and upcoming trials. We were delighted to welcome 162 people to this event and it was a very interesting and thought provoking meeting.

People with PWS Committee: Svetlana Labun

This year saw the establishment of IPWSO's People with PWS Committee, made up of international experts supporting people with PWS to advocate for themselves to ensure their voice is heard. We are a group who work alongside people with PWS to determine and establish the best platforms to express their own needs and wishes, and to exchange ideas on their interests and personal experience, quality of life and wellbeing with each other, and with PWS professionals.

Our objective for 2023 was to determine the best mechanisms for IPWSO to engage with people with PWS so they may share what they think is important. We know everyone with PWS is different. Differing levels of social skills and cognitive abilities should be considered when inviting people with PWS to collaborate with us, so that everyone feels comfortable and encouraged to participate.

We've talked to people with PWS about how they might want to work with IPWSO. We continue to learn from ongoing research on *Listening to the voices of people with PWS across the world*. We've considered the big issues for an international organisation, like language barriers, geographical distance, and different time zones. We want everyone's first engagement with IPWSO to be positive, which is why we're forming a plan for how best to facilitate active and meaningful involvement by people with PWS.

IPWSO's network includes examples of many successful meetings and social activities tailored for people with PWS all over the world. We've collaborated with organisers in Austria, Australia, Germany, Ireland, Malaysia, UK, USA, and more to help us understand best practice in developing and running a PWS group. Our committee members also run such groups themselves.

In 2024 we will continue to learn from countries with existing groups to develop best practice for groups in ways that will help more people living with PWS have the ability to self-advocate and advocate for others. We plan to publish a short guide with advice on holding inclusive meetings for people with PWS. We hope it will help anyone wishing to improve their existing meetings with people with PWS or, excitingly, those wishing to start a new PWS group.

In the longer term we will establish a procedure whereby key developments taking place in IPWSO's work are taken to international PWS groups for feedback. We will empower all people with PWS to participate, whether directly with IPWSO or in their local communities.

Sincere thanks to the Committee Members, Shelly Cordner, Norbert Hödebeck-Stuntebeck, Georgina Loughnan, James O'Brien, Hubert Soyer, Kate Woodcock and Lantz Yap, and especially to everyone with PWS who shared their opinions with us this year.

International advocacy: Marguerite Hughes

In 2023 IPWSO was a member of, or formally affiliated with, the following international organisations:

- European Society of Endocrinology (ESE)
- EURORDIS
- Global Genes
- Healthcare Information for All (HIFA)
- International Alliance of Patients' Organizations (IAPO)
- International Coalition of Organizations Supporting Endocrine Patients (ICOSEP)
- International Collaboration on Rare Diseases and Orphan Drugs (ICORD)
- National Organization for Rare Disorders (NORD)
- Prader-Willi Syndrome Clinical Trial Consortium (PWS-CTC)
- Rare Disease Ghana Initiative (RDGI)
- Rare Diseases International (RDI)

Key IPWSO Advocacy Activities in 2023 included:

- On Rare Disease Day we were active in sharing information and celebrating the lives of people living with rare diseases as part of this global awareness day.
- On European Hormone Day we raised awareness of European Hormone Day and attended the annual meeting of the European Society of Endocrinology Patient Advocacy Group Affiliated Members.
- IPWSO President Tony Holland continues to serve as a board member of the International Alliance of Patients' Organizations (IAPO).
- IPWSO CEO Marguerite Hughes remains an active member of the PWS Clinical Trial Consortium.
- IPWSO joined the National Organization for Rare Disorders (NORD) in the USA.

Diagnostic testing: Marguerite Hughes

For the 21st consecutive year we offered free diagnostic testing for PWS to families unable to access or afford testing in their own countries. This service was provided in collaboration with the Baschirotto Institute for Rare Diseases (BIRD), which is based in Vicenza, Italy.

Tests conducted on behalf of IPWSO in 2023 were paid for through generous 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 this service. Once again in 2023 we used our social media and website to raise awareness of the service, as well as promoting it at relevant conferences and meetings, and in individual correspondence with families and professionals worldwide.

We also produced a new flyer that alerts medical professionals to the key signs and symptoms of PWS at different life stages. Entitled, *Does your patient have PWS?*, this flyer is now available in English, French, Arabic and Portuguese.

In November we signed a new 3-year contract with BIRD, which will ensure that we can continue to provide this service.

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, are available on our website.

Website and Publications: François Besnier and Agnes Hctor

Ensuring that families and professionals have access to accurate and useful information has continued to be a priority for IPWSO this year and it is gratifying to see many new visitors finding us via our website and social media platforms. Keeping the website up to date and working well has been a key task for our staff team.

In response to feedback obtained at the conference of the African Society for Paediatric and Adolescent Endocrinology, we worked with experts from our Clinical and Scientific Advisory Board to develop a simple guide to prompt physicians to consider a diagnosis of PWS at different life stages based on the key signs and symptoms of the syndrome. This was in response to comments about low diagnosis rates in many countries in Africa and a lack of awareness about this rare syndrome. We produced the guide, *Does your patient have PWS?*, in English and then translated it into Arabic, French and Portuguese. All versions are available on our website and many thanks to our networks who have helped distribute the guide.

We also worked with the Famcare Board to prepare two of their new guides for publication. *After the Diagnosis, Relief and Acceptance* and *Preparing for the future: When parents die* are two welcome new additions to our growing collection of guides to support families.

Advice service: Agnes Hctor

This year we have responded to queries from over 100 individuals from 47 different countries. Queries have ranged from simple requests and sign-posting, to more complicated medical questions and involvement in local capacity building. Most requests come from countries where there is no local PWS association and it is gratifying that families can find us online and reach out for our help which we always gladly give.

Working on the advice service reminds us how important access to information is for families supporting a child or adults with this rare syndrome. A parent who is well-informed and has access to support from the international community, can do so much both for their own family as well as supporting other families around them. We know that many people are living without access to Growth Hormone or other medical supports that many of us rely on and there is no simple solution to this, however the ethos of IPWSO, to share information and support is making a real difference to people living with the syndrome and we can feel optimistic about the future.

Many thanks to the volunteers who support the advice service, in particular Dan Driscoll MD, PhD and Susanne Blichfeldt MD, for their unswerving commitment to providing practical and thoughtful guidance.

ABOUT US



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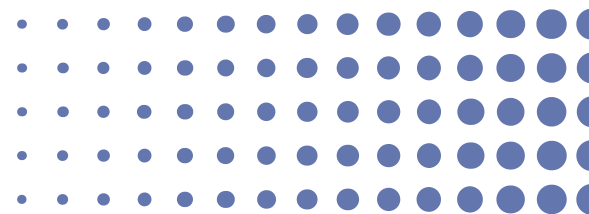
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What is Prader-Willi syndrome?

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.

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