



IPWSO

International
Prader-Willi Syndrome
Organisation

Annual report



20
25

www.ipwso.org

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

Page

- 4** **President's report**
- 6** **Chief Executive Officer's report**
- 9-30** **Financial information**
 - Treasurer's report
 - Independent Examiner's report
 - Financial statements
- 31** **Environmental sustainability**
- 32** **Volunteers**
- 32** **Nominations committee**
- 33-38** **Advisory boards**
 - Clinical and Scientific Advisory Board
 - Famcare Board
 - Professional Providers and Caregivers Board
- 39-60** **Our projects**
 - Equity in action grants
 - Educational outreach
 - United in Hope: International PWS Conference
 - Online events
 - Policy
 - Research
 - People with PWS
 - International advocacy
 - Genetic screening
 - Advice service
- 61-63** **About us**

President's report: Prof Nick Finer

This year has been one of significant transition and progress for IPWSO. There have been important changes in key leadership roles. I was appointed President in July, succeeding Tony Holland, to whom we express enormous gratitude for his dedication, wisdom and many years of service to IPWSO and to the global PWS community, and we were pleased when Tony accepted our invitation to become IPWSO's President Emeritus. Margaret Walker took over as CEO from Marguerite Hughes, who likewise deserves our heartfelt thanks for all that she has done to strengthen and grow the organisation. Both Tony and Marguerite leave a strong legacy on which we are proud to build. We also welcomed new Trustees to the Board and said farewell to other Trustees, Board and Committee Chairs, who we know will remain closely connected to IPWSO and continue to contribute in many ways.

Much has happened during the year to advance our 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.*

A major highlight of the year was the 12th International Prader-Willi Syndrome Organisation Conference, United in Hope (UIH), held in Phoenix, USA. This unprecedented event brought together three key organisations in the field - PWSA USA, FPWR and IPWSO - which collaborated to welcome 1,330 attendees from 29 countries. The conference significantly strengthened global connections among families, carers, clinicians and researchers, deepened understanding of each group's needs and expertise, and laid important foundations for future work, particularly in regions that remain poorly supported. Many new collaborations have already emerged from the meeting, and publications and other outcomes from the Clinical Workshops are now underway.

Important clinical and professional work has also progressed. Consensus documents on PWS in adults and adolescents have been finalised and translated into multiple languages, significantly increasing their global reach and usefulness.

Surveys on PWS in the Asia-Pacific and Latin America regions have gathered data on prevalence, age distribution, growth hormone therapy, peer-to-peer opportunities for adults with PWS, awareness-raising, fundraising and communications. These findings are now shaping strategic planning, helping IPWSO to better understand unmet needs and to target support where it is most needed.

The IPWSO Mental Health Network launched its publication, *Improving mental health and well-being for people with Prader-Willi syndrome*, a major body of work that reflects the complexity and individuality of mental health in PWS, and over the next 12 months we aim to share this widely in accessible and inclusive formats.

Thanks to Friends of IPWSO (USA), we have been able to continue funding grants for small projects, conferences and workshops, empowering underserved communities to build confidence, capacity and visibility, and strongly reflecting our commitment to promote equal opportunities.

Ongoing funding for genetic screening has enabled families in countries without free diagnostic services to confirm a PWS diagnosis. This is a crucial first step in accessing appropriate care and support. Our advice service remains as important as ever. Every enquiry represents a family or professional seeking guidance at a moment of uncertainty or crisis, and this service continues to provide trusted, compassionate and practical support when it is most urgently needed.

Thanks to the generous support of the healthcare industry, our educational outreach continues to grow year on year. We are raising awareness of PWS across the Middle East, Sub-Saharan Africa, and at leading European medical conferences, while our online meetings attract ever-larger audiences, bringing together the global PWS community to tackle, debate, and explore the challenges that matter most.

This year we also remember with deep sadness James (Jim) Gardner, who passed away on 26 April 2025. Jim was a remarkable force in the global Prader-Willi syndrome community and a much-valued and longstanding member of IPWSO. Together with his wife Joan, our dedicated advisor, he supported people with PWS around the world with tireless commitment and generosity. Known for his dry sense of humour, wisdom and deep sense of justice, Jim's insight and kindness enriched everyone who worked with him. He will be profoundly missed, however, his legacy lives on through the lives he touched and the organisations he helped shape.

Finally, I would like to offer my heartfelt thanks to everyone who has welcomed me as President. I am excited to work together to strengthen our community, create new opportunities, and make a lasting difference. IPWSO is an extraordinary community - a family - and it is truly an honour and a privilege to be part of it.

Chief Executive Officer's report: Margaret Walker

Strength in Community

2025 was a year of transition, partnership and renewed global connection for IPWSO.

When I joined IPWSO at the beginning of 2025, I was immediately struck by the extraordinary strength of the PWS community. There is a shared belief that by working together in an organised and collaborative way, we can improve the lives of everyone affected by PWS. I have seen this strength in community repeatedly throughout the year, and it continues to be deeply inspiring.

The first half of the year was focused on delivering the United in Hope: International PWS Conference. I was fortunate that my predecessor, Marguerite Hughes, remained closely involved during the lead-up to this, our flagship event, while providing a comprehensive handover. Held from 24–28 June 2025, the conference was a landmark event for our community and demonstrated the strength of our partnership with the Foundation for Prader-Willi Research (FPWR) and the Prader-Willi Syndrome Association | USA (PWSA | USA). The conference brought together the global PWS community in its largest ever gathering, welcoming 1,330 participants from across the world.

As required by our constitution, IPWSO also held its General Meeting during the conference. Nick Finer was elected as our new President and Chair, succeeding Tony Holland. Several new Trustees joined the Board, and staff ensured a smooth and compliant onboarding process in line with Charity Commission guidance. Many of our departing Trustees remain closely involved in IPWSO's work as Advisors and active members of the PWS community. We are particularly grateful that Tony Holland continues to contribute as Chair of IPWSO's Research and Clinical Trials Committee.

In September, the IPWSO staff met with Tony Holland and Nick Finer for an Away Day. This provided an opportunity to reflect on the achievements under Tony's leadership while looking ahead to the organisation's future under Nick's leadership. Trustees from Asia (Lantz Yap), Africa (Karin Clarke) and Latin America (Johana Quinn and Liane Motta) joined the discussions remotely. The ideas generated during our exchanges are already shaping initiatives for 2026. In particular, we look forward to strengthening our work across regions, building on the valuable survey insights gathered by Lantz Yap in Asia and Johana Quinn in Latin America. We also began discussions about the 2028 International Conference, which will be held in Brazil, making engagement in Latin America a key priority in the coming years.

Like many organisations, we have also faced challenges. Staffing our communications role remained difficult during 2025. I am therefore delighted that Farisha Colbourne will be joining us in January as our new Communications and Engagement Officer, strengthening our ability to connect with the global PWS community.

This year has clearly demonstrated the strength of our global community. I would like to thank the IPWSO Trustees, our volunteers and advisors, our dedicated staff, and our sponsors and supporters - particularly Friends of IPWSO (USA) - whose commitment makes our work possible.

As we look ahead, IPWSO will continue to strengthen global collaboration, expand regional engagement, and ensure that the voices of people living with PWS remain at the centre of our work.

2025 in numbers

13

genetic screening tests provided

100+

advice line enquiries received from

40+

countries

7230

volunteer hours

47

members and contacts in over

120

countries

26

new videos about PWS added to our YouTube channel

1330

delegates from

146

countries attending UIH: International PWS Conference

16

travel fellowships awarded (including strategic)

7

educational outreach conference visits

5

conference grants awarded

8

small projects grants awarded



Financial information

Treasurer's report: Tünde Liplin

I am very pleased, as the new IPWSO Treasurer, to present the financial report for 2025. At the outset, I would like to express my sincere thanks to Craig Moore for his many years of dedicated stewardship of IPWSO's finances. Craig's term of office ended in June 2025 at the General Assembly, where he presented a comprehensive overview of IPWSO's financial performance over the past three years.

We are now pleased to welcome Brett Thompson as a new Trustee to the Committee, and together with Joan Gardner, Michelle Torbert, Margaret Walker and Nora McNairney, we look forward to building on the strong foundations established, consolidating IPWSO's financial position and supporting the organisation's continued sustainability.

The Finance Committee met on 10 occasions over the past year monitoring the income and expenditure, reviewing budgets, assessing bids for our international conference in 2028 and reporting to the Trustees on a regular basis.

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. We report for the most part in US\$.

Results for the year

Income received during the year totalled \$278,858 (2024: \$308,127) of which \$90,648 was restricted and \$188,210 was unrestricted. Restricted income came in the form of grants and donations from bodies within the healthcare industry, corporations and individuals. Expenditure totalled \$298,113 (2024: \$272,982), of which \$160,763 was spent from restricted funds.

There was a net surplus on restricted funds of \$69,863 which has increased the brought forward funds to a total of \$83,656 (2024: \$153,519) to be carried forward. A deficit of \$50,608 on unrestricted funds, when deducted from opening funds, results in a total to be carried forward of \$344,754 (2024: \$294,146).

With regard to finances for the United in Hope: International PWS Conference, the majority of income and expenditure was administered by PWSA | USA, in accordance with agreed financial arrangements. The surplus generated was calculated at the conclusion of the conference and split equally across the three organisations, PWSA | USA, FPWR and IPWSO.

Our closing balance at the end of December 2025 was \$428,410 (2024: \$447,665) and we maintained the following balances in the bank accounts on 31 December 2025:

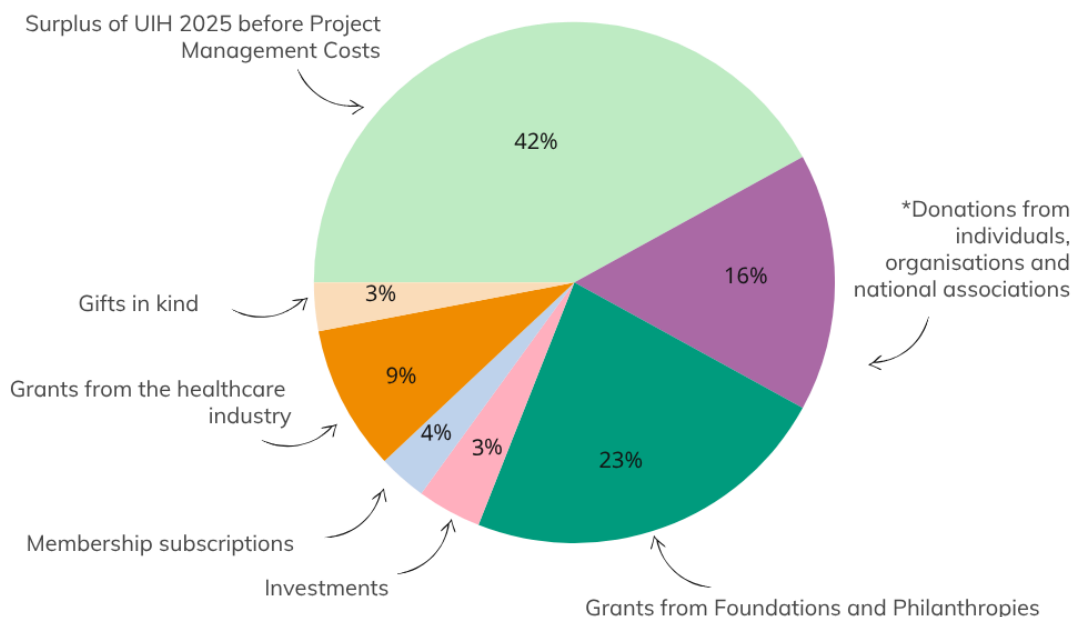
- GBP – 28,690
- EURO – 33,823
- USD – 133,015
- Investment Account GBP 50,000
- Investment Account GBP 112,635

2025 Funding Sources and Breakdown

In 2025 IPWSO received funding from the following sources:

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

*Donations listed above include monthly donations from Jean Phillips-Martinsson totalling \$23,764 annually



The following pharmaceutical industry partners provided direct support to IPWSO in 2025:

- Aardvark Therapeutics
- Acadia Pharmaceuticals
- Palobiofarma
- OT4B
- Soleno Therapeutics

The percentage of IPWSO's income provided directly by industry partners in 2025 was 9% (2024 = 20%).

How we use our funds

Restricted funds supported a wide range of activities over the year including grants for small projects, conferences, workshops and travel scholarships, support for educational outreach activities, diagnostic screening, translation of educational materials and project management costs. Unrestricted income, in the main, supported office running costs, staffing, insurances and costs associated with financial reporting requirements of the Charity Commission and the virtual finance office.

The Financial Statements provide fuller details.

Acknowledgements

Sincere thanks are due 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 Friends of IPWSO (USA), healthcare industry partners, member associations, individual donors and our Honorary President, Jean Phillips-Martinsson, who has been unwavering in her support. Efforts continue to increase our unrestricted income, and this remains a constant challenge for IPWSO and for other small charities in the current economic climate.

Major Donors and sponsors

- Friends of IPWSO (USA)
- Jean Phillips-Martinsson
- Aardvark Therapeutics
- Acadia Pharmaceuticals
- Palobiofarma
- OT4B
- Soleno Therapeutics

Friends of IPWSO (USA)

IPWSO sincerely thanks Friends of IPWSO (USA) for their continued support, which enables us to improve the lives of people with PWS and those who support them. Their generous funding made all of the projects listed here possible in 2025. Further details are available in the *Our Projects* section, beginning on page 39.



Friends support for educational outreach

IPWSO was represented at medical conferences in Côte d'Ivoire, UAE, Kenya, and Nigeria.

Microgrants

- Education and training initiatives (Mexico, Cameroon, Nigeria)
- Multidisciplinary clinics (India, Argentina)
- Research and digital development (Argentina, Bulgaria)
- Community and fundraising events (Portugal)



Travel scholarships

Travel support included UIH scholarships for 10 delegates from 9 countries.

Conferences and training

This support included the ASCPW Asociación Colombiana Síndrome de Prader-Willi training course and the PWSA EG-ME conference held in Egypt.



Learning and innovation

A clinical workshop was delivered for 80 delegates at UIH. 2 attendees were supported to attend the Harvard Rare Diseases Hackathon.

Translations

Simultaneous interpretation into Spanish for our online Family Meeting attended by 173 people.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

INDEPENDENT EXAMINER'S REPORT FOR THE YEAR ENDED 31 DECEMBER 2025

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 2025.

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 2019.

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 2025**

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: 14 May 2026

**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 2025**

	Note	Restricted funds 2025 \$	Unrestricted funds 2025 \$	Total funds 2025 \$	Total funds 2024 \$
INCOME FROM:					
Donations	2	88,548	52,482	141,030	240,744
Charitable activities	3	2,100	126,200	128,300	55,746
Investments	4	-	9,528	9,528	11,637
TOTAL INCOME		90,648	188,210	278,858	308,127
EXPENDITURE ON:					
Charitable activities	5	160,763	137,350	298,113	272,982
TOTAL EXPENDITURE		160,763	137,350	298,113	272,982
NET (EXPENDITURE)/INCOME		(70,115)	50,860	(19,255)	35,145
Transfers between funds	13	252	(252)	-	-
NET MOVEMENT IN FUNDS		(69,863)	50,608	(19,255)	35,145
RECONCILIATION OF FUNDS:					
Total funds brought forward		153,519	294,146	447,665	412,520
Net movement in funds		(69,863)	50,608	(19,255)	35,145
TOTAL FUNDS CARRIED FORWARD		83,656	344,754	428,410	447,665

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.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**BALANCE SHEET
AS AT 31 DECEMBER 2025**

	Note	2025 \$	2024 \$
CURRENT ASSETS			
Debtors	10	3,060	4,000
Investments	11	219,212	266,141
Cash at bank and in hand		224,333	191,671
		446,605	461,812
CURRENT LIABILITIES			
Creditors: amounts falling due within one year	12	(18,195)	(14,147)
NET CURRENT ASSETS		428,410	447,665
TOTAL NET ASSETS		428,410	447,665
CHARITY FUNDS			
Restricted funds	13	83,656	153,519
Unrestricted funds	13	344,754	294,146
TOTAL FUNDS		428,410	447,665

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



.....
Professor Nicholas Finer
Trustee and Chair

Date: 13 May 2026

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

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

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.

The Trustees do not consider that there are any material uncertainties in relation to going concern.

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 2025**

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.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

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 CURRENT ASSET INVESTMENTS

Current asset investments are short-term highly liquid investments with a short maturity of greater than three months from the date of acquisition or opening of the deposit or similar account, but less than a year.

1.11 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.

1.12 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.

1.13 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 2025**

2. INCOME FROM DONATIONS

	Restricted funds 2025 \$	Unrestricted funds 2025 \$	Total funds 2025 \$	Total funds 2024 \$
Donations	7,169	52,482	59,651	101,407
Grants	81,379	-	81,379	139,337
TOTAL 2025	<u>88,548</u>	<u>52,482</u>	<u>141,030</u>	<u>240,744</u>
TOTAL 2024	<u>183,816</u>	<u>56,928</u>	<u>240,744</u>	

Included in donations is a \$8,068 (2024: \$6,405) gift in kind relating to legal advice.

3. INCOME FROM CHARITABLE ACTIVITIES

	Restricted funds 2025 \$	Unrestricted funds 2025 \$	Total funds 2025 \$	Total funds 2024 \$
Member subscriptions	-	9,916	9,916	9,728
Genetic screening	2,100	-	2,100	5,427
Conference registration fees	-	116,284	116,284	40,591
TOTAL 2025	<u>2,100</u>	<u>126,200</u>	<u>128,300</u>	<u>55,746</u>
TOTAL 2024	<u>5,427</u>	<u>50,319</u>	<u>55,746</u>	

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

4. INVESTMENT INCOME

	Unrestricted funds 2025 \$	Total funds 2025 \$	Total funds 2024 \$
Money market interest	9,528	9,528	11,637
TOTAL 2024	11,637	11,637	

5. ANALYSIS OF EXPENDITURE BY ACTIVITIES

	Activities undertaken directly 2025 \$	Grant funding of activities 2025 \$	Support costs 2025 \$	Total funds 2025 \$	Total funds 2024 \$
Charitable expenditure	207,312	75,731	15,070	298,113	272,982
TOTAL 2024	221,087	6,730	45,165	272,982	

ANALYSIS OF DIRECT COSTS

	Total funds 2025 \$	Total funds 2024 \$
Staff costs	133,620	113,635
Conferences and events costs	59,398	99,522
Genetic screening	3,337	4,729
Website costs	734	3,201
Translations	10,223	-
	207,312	221,087

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

5. ANALYSIS OF EXPENDITURE BY ACTIVITIES (CONTINUED)

ANALYSIS OF SUPPORT COSTS

	Total funds 2025 \$	Total funds 2024 \$
Accountancy and bookkeeping fees	12,181	10,676
(Gain)/loss on foreign currency conversion	(27,735)	12,028
Advertising and marketing	192	284
Insurance	7,075	3,709
IT software and consumables	2,434	2,420
Bank charges	1,494	1,076
Miscellaneous expenses	2,853	1,340
Office running costs	6,425	5,982
Professional and consultancy fees	10,151	7,650
	15,070	45,165

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

6. ANALYSIS OF GRANTS

	Grants to Institutions 2025 \$	Grants to Individuals 2025 \$	Total funds 2025 \$	Total funds 2024 \$
Microgrants	39,619	36,112	75,731	6,730
TOTAL 2024	<u>5,147</u>	<u>1,583</u>	<u>6,730</u>	

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

NAME OF INSTITUTION	2025 \$	2024 \$
Children's Hospital Buenos Aires (Sofia Suco Valle)	2,000	-
PWSA Egypt-Middle East	13,246	-
PWSA China	2,000	-
Asociación Colombiana Síndrome de Prader-Willi	5,000	-
IPWSA (India)	1,996	-
African Society for Paediatric and Adolescent Endocrinology	5,000	-
Kenya Paediatric Association	3,772	-
RDC Tech & SPINE	2,000	-
PWSA Bulgaria	1,987	-
Associação SPW Portugal	1,485	1,200
Foundation for Prader-Willi Research	1,000	-
Healthcare Information For All	133	-
University Kebangsaan Malaysia	-	1,000
Aster CMI Hospital	-	700
ASOPRAWI (PWS Costa Rica)	-	1,085
Associação Brasileira da Síndrome de Prader-Willi	-	1,162
	<u>39,619</u>	<u>5,147</u>

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

7. INDEPENDENT EXAMINER'S REMUNERATION

	2025	2024
	\$	\$
Fees payable to the CIO's independent examiner for the independent examination of the CIO's annual accounts	2,067	1,969
Fees payable to the CIO's independent examiner in respect of:		
Preparation of statutory financial statements	3,354	2,809
Bookkeeping services	4,753	4,599

8. STAFF COSTS AND KEY MANAGEMENT PERSONNEL

	2025	2024
	\$	\$
Wages and salaries	126,772	106,690
Social security costs	2,800	3,502
Contribution to defined contribution pension schemes	4,048	3,443
	133,620	113,635
	133,620	113,635

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

	2025	2024
	No.	No.
Staff	4	4
	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. During the year, the CEO received remuneration (comprising gross salary, employer's national insurance and employer's pension contributions) totalling \$36,807 (2024: \$20,281).

9. TRUSTEES' REMUNERATION AND EXPENSES

During the year, no Trustees received any remuneration or other benefits (2024 - \$NIL).

During the year ended 31 December 2025, expenses totalling \$11,166 were reimbursed or paid directly to 9 Trustees (2024 - \$7,556 to 6 Trustees). These expenses related to travel, accommodation and subsistence.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

10. DEBTORS

	2025	2024
	\$	\$
Trade debtors	326	4,000
Prepayments	2,734	-
	3,060	4,000
	<u>3,060</u>	<u>4,000</u>

11. CURRENT ASSET INVESTMENTS

	2025	2024
	\$	\$
Money market investments (maturing between 6 months and 1 year)	219,212	266,141
	<u>219,212</u>	<u>266,141</u>

12. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2025	2024
	\$	\$
Trade creditors	8,182	2,052
Other taxation and social security	2,298	1,826
Other creditors	901	640
Accruals	6,814	9,629
	18,195	14,147
	<u>18,195</u>	<u>14,147</u>

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

13. STATEMENT OF FUNDS

STATEMENT OF FUNDS - CURRENT YEAR

	Balance at 1 January 2025 \$	Income \$	Expenditure \$	Transfers in/out \$	Balance at 31 December 2025 \$
UNRESTRICTED FUNDS					
General Funds	294,146	188,210	(137,350)	(252)	344,754
RESTRICTED FUNDS					
ASPED 2025	-	6,879	(6,887)	8	-
Attendance at educational conferences	39,654	10,462	(24,544)	-	25,572
Genetic screening	926	2,100	(3,125)	99	-
Clinical Trials Update Meetings	-	4,158	(4,158)	-	-
Friends: translations	1,094	-	(240)	-	854
Friends: meetings and workshops	-	17,250	(16,146)	650	1,754
Friends: 3 year grant	90,623	-	(40,247)	-	50,376
Friends: microgrants	2,404	9,200	(9,454)	(1,200)	950
Friends: travel and strategic fellowships for 12th International Conference	11,001	17,250	(25,868)	(2,383)	-
Translation and interpretation	5,015	7,500	(12,796)	281	-
IPWSO Caregivers' Forum	2,000	-	(2,000)	-	-
12th International Conference - other funding	802	2,549	(1,809)	(1,542)	-
Friends: funds for ASPAE 2025	-	4,600	(4,787)	187	-
Friends: PWS 2025 Workshop USA	-	8,000	(8,000)	-	-
Hackathon Funds	-	700	(702)	2	-
Friends: educational outreach	-	-	-	4,150	4,150
	<u>153,519</u>	<u>90,648</u>	<u>(160,763)</u>	<u>252</u>	<u>83,656</u>
TOTAL OF FUNDS	<u><u>447,665</u></u>	<u><u>278,858</u></u>	<u><u>(298,113)</u></u>	<u><u>-</u></u>	<u><u>428,410</u></u>

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

13. STATEMENT OF FUNDS (CONTINUED)

STATEMENT OF FUNDS - PRIOR 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
Genetic screening	829	5,427	(5,330)	-	926
6th International Caregivers Conference - Berlin	12,001	19,647	(65,948)	34,300	-
Friends: translations	1,098	-	(4)	-	1,094
Friends: meetings and workshops	23,064	-	(16,300)	(6,764)	-
Friends: travel scholarship PCC (Berlin)	4,600	-	(3,561)	(1,039)	-
Friends: 3 year grant	-	100,000	(9,377)	-	90,623
Friends: microgrants	11,050	-	(7,597)	(1,049)	2,404
Friends: filming PPC 2024 conference	4,800	-	-	(4,800)	-
Friends: travel and strategic fellowships for 12th International Conference	-	11,500	(4,410)	3,911	11,001
Translation and interpretation	-	5,000	15	-	5,015
IPWSO Caregivers' Forum	-	4,000	(2,000)	-	2,000
12th International Conference - other funding	-	832	(30)	-	802
	<u>74,942</u>	<u>189,243</u>	<u>(145,225)</u>	<u>34,559</u>	<u>153,519</u>
TOTAL OF FUNDS	<u>412,520</u>	<u>308,127</u>	<u>(272,982)</u>	<u>-</u>	<u>447,665</u>

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

13. STATEMENT OF FUNDS (CONTINUED)

ASPED 2025 - Grant from Friends of IPWSO USA to cover travel and subsistence costs for IPWSO representatives attending and presenting at the 2025 Arab Society for Paediatric Endocrinology and Diabetes (ASPED) Conference.

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.

Genetic Screening – this fund represents monies received from OT4B and raised from fundraising campaigns and is used to support genetic screening for PWS.

Clinical Trials Update Meetings - Donations from Aardvark Therapeutics Inc, Palobiofarma SL, Arcadia and Soleno Therapeutics Inc to fund IPWSO's 2025 research and clinical trials update meeting held on 11 September 2025.

Friends funds for ASPAE 2025 - Grant from Friends of IPWSO (USA) to fund travel scholarships to enable selected African delegates to attend the 2025 African Society for Paediatric and Adolescent Endocrinology (ASPAE) conference.

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 meetings and workshops – funding from Friends of IPWSO (USA) to support national and regional conferences on Prader-Willi syndrome.

Friends Travel Fellowship - Grant from Friends of IPWSO (USA) to support national and regional conferences, meetings or workshops focused on Prader-Willi syndrome in areas where there is currently limited knowledge about PWS. The grants may be used to cover costs such as venue rent, meals and travel.

Friends PWS 2025 Workshop - Grant from Friends of IPWSO (USA) to cover a portion of the costs of a Prader-Willi syndrome clinical workshop held on June 24 2025 in Phoenix, Arizona in the same venue as the United in Hope International PWS Conference.

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

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

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.

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.

Hackathon Funds - Grant from Friends of IPWSO (USA) to cover the costs for a representative of

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

13. STATEMENT OF FUNDS (CONTINUED)

IPWSO to attend the 2025 Harvard Rare Disease Hackathon supporting students to produce solutions to the challenges relating to Prader-Willi syndrome.

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

Funds to support the IPWSO Caregivers' Forum – funds to support the organisation of a Caregivers Forum, a new initiative launched in 2024.

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

Friends educational outreach - grant from Friends of IPWSO (USA) to cover the 2026 educational outreach programme.

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 YEAR

	Restricted funds 2025 \$	Unrestricted funds 2025 \$	Total funds 2025 \$
Current assets	91,956	354,649	446,605
Creditors due within one year	(8,300)	(9,895)	(18,195)
TOTAL	<u>83,656</u>	<u>344,754</u>	<u>428,410</u>

ANALYSIS OF NET ASSETS BETWEEN FUNDS - PRIOR YEAR

	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	<u>153,519</u>	<u>294,146</u>	<u>447,665</u>

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

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 \$4,048 (2024 - \$3,443). \$901 (2024 - \$640) 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 7,230 hours compared with 5,395 hours by staff (2024: 7,199 hours and 4,900 hours, respectively).

17. RELATED PARTY TRANSACTIONS

During the year, donations totaling \$313 (2024: \$654 from 3 Trustees) were received from 2 Trustees and \$23,764 (2024: \$21,710) from our Honorary President, Jean Phillips Martinsson. There are no conditions attached to these donations.

Environmental sustainability



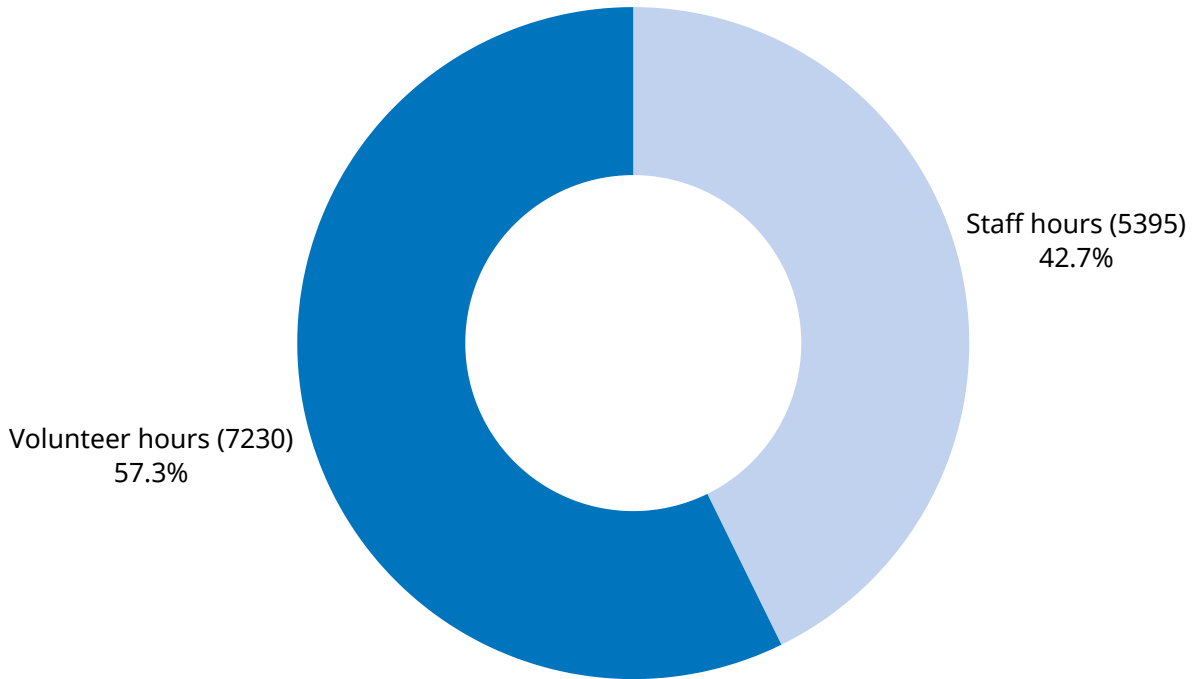
IPWSO's commitment to environmental sustainability continued in 2025 following our signing of the Climate and Environmental Leadership Principles formulated by the Association of Chief Executives of Voluntary Organisations (ACEVO) in the UK in 2023.

We believe IPWSO achieves 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. Nevertheless, throughout 2025, 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. At our United in Hope: International PWS Conference, we implemented a paperless policy, minimised the use of single-use plastics and offered locally sourced seasonal and more plant-based food options.



Volunteers

As in previous years, the hours committed by IPWSO volunteers exceed 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 and early 2025 to prepare the slate of recommended candidates for the positions of IPWSO President and new Trustees, and to ensure our processes were fair, transparent, and robust. The Committee fulfilled its brief at the General Assembly, held in June 2025, where candidates were officially approved and will serve from June 2025 until the General Assembly in 2028.

Our thanks go to all those from around the world who put themselves forward - the task of selecting candidates was particularly challenging given the high number and exceptional quality of applications received. Our sincere thanks to Colin Pearson and David Gordon for all their oversight and advice in this regard.

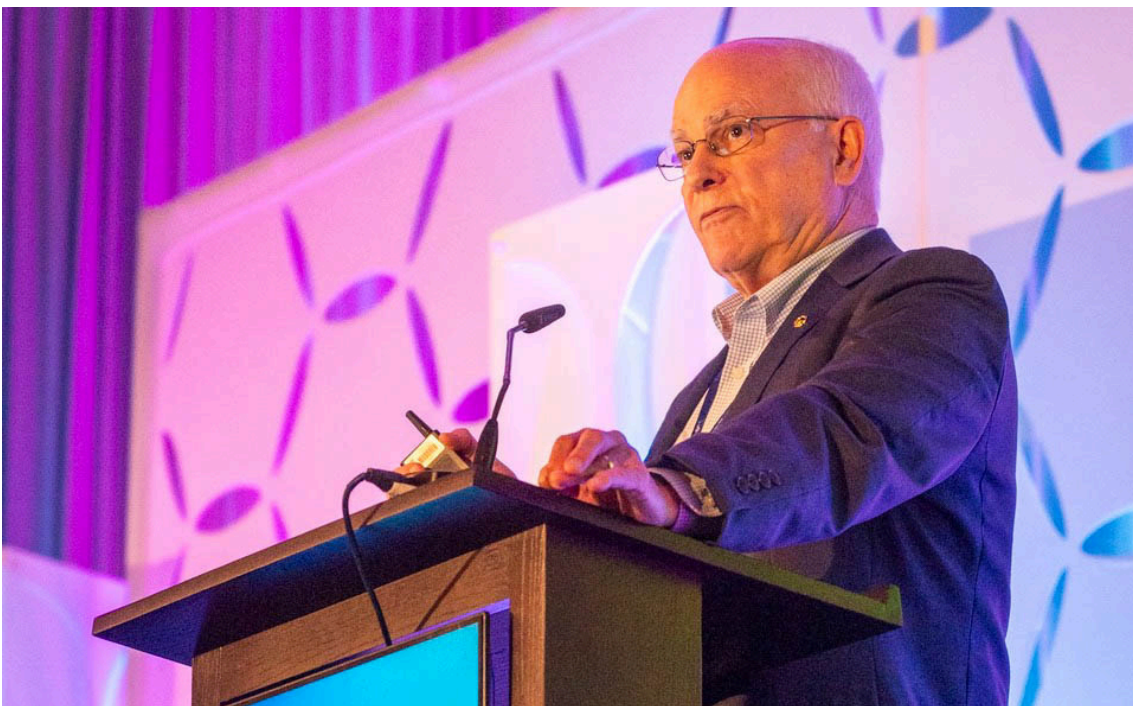
Advisory boards

Clinical and Scientific Advisory Board: Charlotte Höybye, 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.

In 2025, we marked an important transition as Dan Driscoll, MD, PhD stepped down as Chair of the CSAB. During his tenure, he provided thoughtful leadership, strong scientific guidance, and a deep commitment to the mission of the organisation. We are sincerely grateful for his service and for the lasting contribution he has made to IPWSO.



Dan Driscoll, MD, PhD, presenting at the United in Hope: International PWS Conference

Four new members were added this year – Akhil Maheshwari, Professor in neonatology, Jennifer Miller, Professor in paediatric endocrinology, Shawn McCandless, Professor in medical genetics, and Nick Finer, Adult endocrinologist and President of IPWSO

12th International Prader-Willi Syndrome Organisation Conference:

The CSAB held a Clinical and Scientific (C&S) meeting as part of the United in Hope: International PWS Conference in Phoenix, Arizona, USA, in June 2025. The meeting was a great success and well-attended by 413 participants from 29 countries. The C&S Programme offered 60 sessions filled with interesting talks on important topics and new insights, including 32 oral abstracts, 20 lightning talks and 95 poster abstracts. Four appreciated pre-conference workshops on current topics were held by the Foundation for Prader-Willi Research and IPWSO on: GLP-1 agonists, Therapeutics for behaviour and mental health concerns, Health equity in clinical research and care, and ageing.

CSAB's commitment to science and its accessibility:

Scientific papers: Joyce Whittington has kindly continued to prepare quarterly listing of scientific papers published in peer-reviewed journals. The lists give a focused overview of basic science and a broad range of clinical topics. The lists are available for all on our website:

<https://ipwso.org/information-for-medical-professionals/research-papers/>

Publications from CSAB:

The CSAB has updated consensus documents on adult and adolescent care and management, which have been translated into several languages. Updating of the infant and children consensus documents are ongoing. A video on the "The genetics of PWS" was created.

Treatment with GLP-1 agonists is a hot topic and a review by Ann Manzano, *Is there a role for GLP-1 Receptor Agonists in Prader-Willi Syndrome?*, has been published on IPWSO's website. In addition, a report from the workshop on GLP-1 agonists at UIH has been published (Finer N et al. *Diabetes Obes Metab.* 2025).

Global solidarity and collaboration:

During 2025 members of the CSAB have represented IPWSO at several meetings and conferences around the world. The representation has consisted of dissemination of information about PWS and IPWSO, giving talks and reaching out to health care professionals primarily in parts of the world where knowledge of PWS is limited or where support is needed. Through these efforts many new connections have been made and insights achieved.

Famcare Board: Verena Gutmann

Success and transformation

This year has been both busy and transformative for Famcare. The board met regularly, holding ten meetings across the year, and welcomed new members who further enhance the diversity of our global PWS community. These positive developments have strengthened our ability to represent and support families around the world.

In June, Georgina Loughnan and Verena Gutmann (pictured, with IPWSO Trustee Tünde Liplin) attended the United in Hope: International PWS Conference in Arizona, where they presented at the Family Conference. Their session offered a comprehensive and engaging overview of Famcare's work, highlighting key Famcare topics drawn from articles published on the IPWSO website. The presentation was very well received and generated strong interest from attendees. As a direct result, four delegates expressed interest in joining the Famcare Board: Cathy Mallow (Canada), Elizabeth Oyenusi (Nigeria), Marina Wetzel (Switzerland), and Arami Zhu (USA).

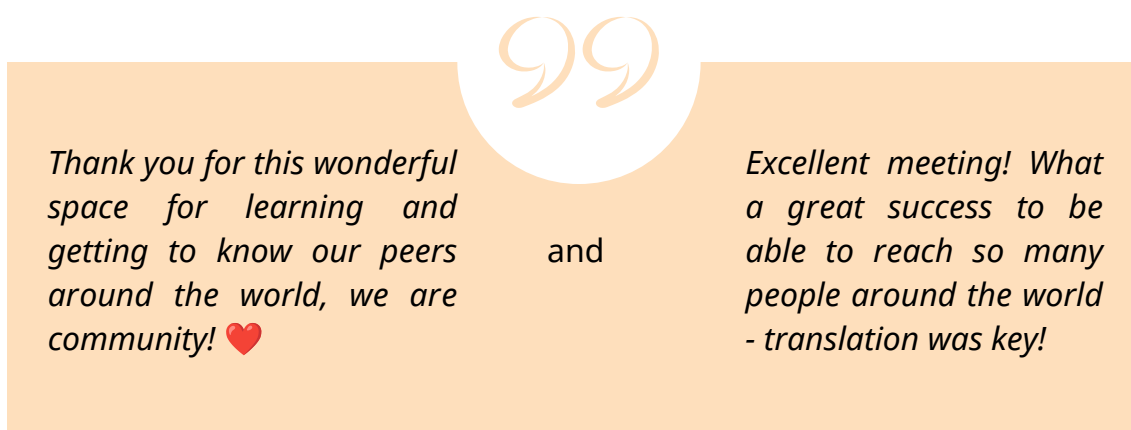


Georgina Loughnan, IPWSO Trustee Tünde Liplin, and Verena Gutmann
at the United in Hope: International PWS Conference

The conference also provided valuable opportunities for in-person connection. Georgina and Verena were able to meet colleagues face to face, strengthening relationships, securing future speakers and identifying topics for the Famcare Family Zoom Meetings.

In 28 October, the 4th International Famcare Online Information Session took place under the theme: Starting Good Habits Early – Information for Young PWS Families. Dr Constanze Lämmer, drawing on her wide professional experience, spoke about “Caring for an Infant and Young Child with PWS.” Tünde Liplin, mother of a son with PWS and President of the Hungarian PWS Association, shared the journey of building family life with a child with PWS in a country where support systems had to be created from the ground up. She offered practical and universally helpful advice for young families. Liane Motta from the Brazilian PWS Association delivered a heartfelt and inspiring talk about raising her daughter with PWS.

Accessibility was a key success of this event. María Elvira García Ronderos, Famcare Board member from Colombia, organised simultaneous translation from English into Spanish, opening the meeting to many more families across the Spanish-speaking world. The impact was clear in the feedback, including comments such as:



2025 has been a year of significant change for Famcare with founding members Georgina and Verena standing down after playing major roles in its development. Their dedication, vision, and commitment have shaped Famcare into what it is today, and they will be very much missed.

At the same time, we look ahead with optimism. Karin Clarke (South Africa), supported by Dr Susanne Blichfeldt (Denmark), will lead Famcare into its next exciting phase. With new leadership and a growing, diverse team, Famcare is well placed to continue strengthening support for families and building an even more connected global PWS community.

Professional Providers and Caregivers Board: Lynn Garrick

The past year has been a period of meaningful growth, collaboration, and measurable impact for the PPCB. We also acknowledge important transitions on the board this year, as founding PPCB member and former Chair Norbert Hödebeck-Stuntebeck and Co-Chair Laura Keane stepped down. Their leadership and many years of dedication have been instrumental in shaping the PPCB and advancing its mission.

It has been my pleasure to work alongside such a dedicated group of professionals: Larry Genstil, Myles Kelly, Patrice Carroll, Neil Gumley, Lynsey Moorehouse, who joined this year, Hubert Soyer, and Mary K. Ziccardi. A special thank you to Shelly Cordner, on staff at IPWSO, who supports this group in all we do. Their collective expertise and global perspective continue to strengthen IPWSO's mission and improve the quality of care for individuals with PWS.

The highlight of the year was the United in Hope: International PWS Conference, an unprecedented effort that brought together IPWSO, PWSA | USA, and FPWR for a unified international conference. Held on 25–26 June, the Professional Providers Conference (pictured next page) welcomed 161 attendees, featured 19 expert speakers, and showcased 5 poster abstracts. Feedback was overwhelmingly positive, with attendees reporting increased confidence in care practices, strengthened professional networks, and enhanced understanding of interdisciplinary approaches. Centred on the theme “Sharing the Care,” the conference reinforced a whole-person model of support across clinical, residential, and community-based services.



All of the sessions I attended were well presented and very informative. The attendees asked questions in a respectful manner and the whole environment encouraged honest and open discussion.

– UIH PPC attendee feedback

Another key outcome this year was the continued development of the Caregivers' Forum, a virtual space connecting professional caregivers worldwide. With over 200 registered participants, it is now a vital platform for shared learning and peer support. IPWSO supported this community through regular meetings, resources, and international networking. Topics driven by member input (grief, cultural diversity, restrictive practices, and establishing PWS residential care) have ensured relevance and practical impact.

Looking ahead, planning is underway for the 7th International PWS Caregivers' Conference in 2027, which will again bring caregivers together to collaborate, learn, and advance global best practices. In parallel, the PPCB is updating the Best Practice Guidelines for PWS Residential Care, originally developed following the 2009 Herne Conference, in collaboration with caregivers and providers worldwide to ensure guidance reflects current evidence, lived experience, and diverse care settings.

Together, these outcomes demonstrate sustained progress toward strengthening the global PWS caregiving community and supporting individuals with PWS to live the highest possible quality of life.



Mary K. Ziccardi, Patrice Carroll and Lynn Garrick welcome delegates to the Professional Providers Programme at the United in Hope: International PWS Conference

Our projects

Equity in Action Grants: Lynn Garrick

Guided by a commitment to fair access and meaningful impact, the Grants Committee worked in 2025 to distribute our funds and so strengthen our global PWS community, particularly in underserved areas. I am grateful to my colleagues on the Grants Committee - Susanne Blichfeldt, Georgina Loughnan, Norbert Hödebeck Stuntebeck and Nora McNairney for all their input in assessing applications over the last year.

We are hugely indebted to Friends of IPWSO (USA) who enabled these awards, the impact of which is reflected in the testimonials and in the real, lasting change they create - supporting professionals to access knowledge, build local capacity, strengthen networks and bring vital PWS resources to communities that would otherwise be left behind.

Travel scholarships:

United in Hope: International PWS Conference, Phoenix, USA
and the 16th African Society for Paediatric and Adolescent Endocrinology (ASPAE) Conference, Abidjan, Côte d'Ivoire.



Thank you IPWSO, for believing in the power of education, connection and opportunity. You have opened the door to an experience that will leave a lasting impact on my work and my heart. I look forward to reuniting at the next conference, equipped with even more tools, knowledge and enthusiasm to support people with PWS and their families. With heartfelt gratitude.

– Claudia Rubio, Psychologist, Mexico, UIH 2025 Delegate



The International Prader-Willi Syndrome Conference is not just a platform for exchange but also a bridge connecting the global PWS community. This experience deepened my understanding of the importance of unity, collaboration and shared progress. In the future China's PWS organisation will continue upholding this philosophy bringing more hope to patients and their families.

– Mr Lin Xiojing, PWSA China, UIH 2025 Delegate



A particular session on the second day of the family programme – “PWS Around the World” Professor Tony Holland, Immediate Past President of IPWSO, inspired me greatly about the work that is being done in making sure that many countries are covered and efforts are being made at reaching the unreached. It opened my eyes to the enormous work that still needs to be done, especially concerning case findings in Sub-Saharan Africa (except South Africa) and optimal or near-optimal care with children with PWS and families.

– Dr Elizabeth Eberechi Oyenusi, President of the African Society for Paediatric and Adolescent Endocrinology, Nigeria, UIH 2025 Delegate

With the generous support provided by Friends of IPWSO (USA), we awarded 11 travel scholarships to parents and professionals across the globe, including delegates from Argentina, Bulgaria, Brazil, China, Colombia, Egypt, Kenya, Mexico and Nigeria. This initiative was also supported by Landsforeningen for Prader-Willis syndrom (PWSA Norway).

We provided financial assistance to four endocrinologists to attend the 16th ASPAE Conference in Abidjan, Côte d'Ivoire in 2025:

- Dr Oluwakemi Funmilola Ashubu, Paediatric Endocrinologist, Nigeria
- Dr Brenda Oeba, Paediatric Endocrinologist, Kenya
- Dr Taibat Raji, Paediatric Endocrinologist, Nigeria
- Dr Emmanuel Ameyaw, Paediatric Endocrinologist, Ghana

Reflecting on the value of her attendance Dr Ashubu said:



”

The large poster I received has now been posted on the wall in our clinic for clinicians to enhance their knowledge of the genetic syndrome. I will be organizing a grand round on PWS where I will be emphasizing on having a high index of suspicion for PWS especially when failure to thrive and hypotonia is noticed in the newborn / infant.

Microgrants projects:

Grants are awarded up to the value of \$2,000 in this initiative, which is 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.

There was a high level of interest and awards were issued for projects including website development (PWSA Bulgaria); support for multidisciplinary clinics - which reduces costs and time for families and helps support adherence to treatment plans (PWSA India and the Children's Hospital Ricardo Gutierrez in Buenos Aires, Argentina); continuous medical education initiatives in Cameroon, led by Dr Ritha Carole, and a presentation at the 46th Annual Scientific Conference of the Endocrine and Metabolism Society of Nigeria by Dr Elizabeth Oyenui.

The Fundación María José Síndrome Prader-Willi, Mexico, produced some fun educational materials for peer learning, and support for the development of an AI tool to assist in identifying PWS markers was provided to Fundación SPINE, Argentina, and RDC Tec, UK. PWSA EG-ME translated PWS materials into Arabic and the Associação Portuguesa Prader Willi (APPW, Portugal) held a very successful and well attended 2nd Solidarity Annual Gala.

Conference and workshops:

ASCPW Asociación Colombiana Síndrome de Prader-Willi received support to deliver an online workshop. The course, delivered by Fundación SPINE, Argentina, and led by Dr Jorgelina Stegmann, provided multidisciplinary training for professionals and families involved in the care of individuals with PWS. Ten virtual sessions reached 653 participants across Latin America, supported by recorded materials made available online for future use. The programme concluded with an in-person mentoring phase in November, including practical activities involving children and their caregivers.

This part of the programme focused on supervised, hands-on training led by the SPINE team, enabling professionals to apply practical strategies directly with individuals with PWS. Seven individuals with PWS and 12 multidisciplinary professionals participated, reinforcing the value of structured, consistent, and tailored interventions delivered through a multidisciplinary approach.



I would like to express my sincere gratitude for the experience of spending time with children with PWS and witnessing their diverse abilities. Having the opportunity to accompany them, guide them, and learn alongside them was truly meaningful for me.

Every moment helped me see the world from a more human, patient, and empathetic perspective. Their way of expressing themselves, their daily effort, and the joy with which they face each challenge left a lasting impression that I will always carry with me.

I am also grateful to those who provided us with guidance and tools to support them in the best possible way. Thanks to their direction, we were able to work with respect, equality, and compassion, recognizing that we all share the same value and deserve the same opportunities.

– Mónica Chocue, course participant



The recently formed PWSA Egypt and Middle East Association (PWSA EG-ME) delivered their first hybrid conference with an in-person camp and online presentations from experts from around the world. Sarah Kasaby, Vice President reflected:



It was magical... it was the first time all these families came together. We've been talking for years on WhatsApp, and over the phone, but this is the first time that we all came together and saw each other for the first time, and I think it helped us It offered incredible opportunities for families to meet PWS specialists and professionals from around the world to learn more about PWS, ask valuable questions about their loved ones, and share their own experiences as parents and caregivers.

– Sarah Kasaby, Vice President, PWSA Egypt and Middle East



These grants represent investments in people, partnerships and possibility, and we are confident that they widen access to knowledge and care and help build a more connected and equitable future for all. If you would like to help support such initiatives, please do reach out to us and to stay informed of new grant rounds in 2026, sign up to receive the [IPWSO newsletter](#) or visit our [website](#).

We look forward to supporting many more projects throughout 2026.

Harvard Rare Diseases 2025 Hackathon:

In collaboration with the National Organization for Rare Disorders in the USA, a team of Harvard students organised an annual Harvard Rare Disease Hackathon. With the support of Friends of IPWSO (USA) Lynn Garrick and Tony Holland represented IPWSO.

The goal of the Hackathon is to bring together brilliant minds to explore computational solutions for rare diseases, leveraging the power of open science and genomic data. The ultimate aim of this Hackathon is to produce solutions that can be scaled to improve the lives of people with rare diseases. It is an expectation of the initiative that students will have the opportunity to interact with inspiring patients, caregivers, physicians, and scientists involved in relevant rare diseases areas. IPWSO tasked the student to work on 3 challenges:

1. How can we create innovative strategies to raise awareness of PWS among medical professionals globally and promote the availability and use of genetic testing for timely and accurate diagnoses?
2. Design an internet-based platform that provides parents, caregivers, and healthcare professionals with tailored information, cultural and linguistic accessibility, treatment resources and referral pathways, and ease of use.
3. Develop a solution that enables reliable, long-term health tracking for individuals with PWS across various countries and cultural settings.

Tony reported:



Throughout the event, we engaged with a wide range of participants - including university students, early-career professionals, and mentors - who showed a genuine interest in learning about PWS and its complex challenges. The enthusiasm and curiosity among the students were especially encouraging ... Social media activity surrounding the Hackathon was robust, with numerous posts from student participants highlighting their work and explicitly mentioning PWS. This increased online visibility helped expand awareness well beyond the event itself and contributed to a growing conversation about the role of technology in supporting rare disease communities.

Lynn noted that one particularly promising outcome was that a team working on a PWS-related project was approached by a representative from the Prader-Willi Syndrome Association in the UK.

Lynn said:



This initial outreach has opened the door to potential collaboration, underscoring the value of such events in forging connections between innovators and advocacy organisations.



The Hackathon served as a powerful reminder of the potential that exists when emerging talent is invited to address real-world health challenges. We look forward to continuing to support and encourage these kinds of collaborative, cross-disciplinary efforts, which bring hope and progress to the PWS and broader rare disease communities.

Translations and interpretation:

Providing translation and interpretation is essential to ensuring that knowledge is accessible to all, regardless of language or location. Funds to support these services, provided this year by Soleno Therapeutics and Friends of IPWSO (USA) have enabled us to remove barriers that can exclude individuals and communities from learning, participation, and decision-making. We are hugely grateful for this investment which meant that we could provide an interpreter for the Famcare online meeting and translation of the CSAB's recently updated consensus documents on adults and adolescents with Prader-Willi syndrome. These have been translated into multiple languages including Arabic, Bulgarian, Chinese, Georgian, Romanian, Spanish and Turkish. These are all available to download from our website.

UIH 2025 Clinical Workshop:

Friends of IPWSO (USA) enabled a clinical workshop / fringe meeting to be held at the UIH 2025 conference which brought together 80 delegates, mainly from clinical backgrounds, but also parents and professionals working in residential care settings. Four workstreams were identified and while FPWR is leading on the project, IPWSO has representation and is collaborating on outputs on each of the four streams:

Workshop 1 focused on GLP-1 agonists in Prader-Willi syndrome and examined their emerging role in clinical care. Our President, Nick Finer, was pleased to report on the subsequent publication of "Recommendations for real-world evidence of efficacy and safety of GLP-1 agonists in Prader-Willi syndrome" in the September edition of *Diabetes, Obesity and Metabolism*, which discusses the growing use of GLP-1 medications in PWS. As prescriptions of drugs such as semaglutide and tirzepatide increase, the authors noted the limited evidence available and agreed on a practical set of measures to track in everyday care, from changes in hunger and behaviour to gastrointestinal symptoms and basic lab results. Participants at the workshop also backed plans for a shared clinical database to help build clearer real-world evidence on the benefits and risks of GLP-1 therapies for the PWS community. Readers can access the full document [here](#) or by requesting a copy from the IPWSO office.

Workshop 2 addressed therapeutics for behavioural and mental health concerns in people with PWS. The workshop used case-based learning to examine how best to evaluate and manage individuals with PWS who are experiencing mental health concerns. Three progressive case studies were presented by Drs Holland and Singh, with a facilitated discussion to highlight key points in the evaluation of individuals with PWS and development of a plan to address mental health issues. The goal is to submit a pedagogical report.

Workshop 3 examined health equity in PWS clinical research and care. Participants discussed concepts of health equity in PWS clinical care and research. Sources of disparities across countries and within-country were discussed, as well as strategies to reduce inequities. The three advocacy groups, FPWR, PWSA USA and IPWSO continue to meet to advance the recommendations developed by workshop participants.

Workshop 4 considered ageing in PWS, with a focus on optimising care across the lifespan, defining key issues, and identifying potential solutions. As a result of this session, a PWS Ageing Interest Group has been established. Planned follow-up includes ongoing discussion with the group and engagement with INfoMED to support future work in this area.

Educational outreach across Europe, MENA and Sub-Saharan Africa: Nora McNairney

In 2025 IPWSO had a presence at seven medical conferences, and for the first time our outreach extended into the Middle East region with attendance at the Middle East and North African (MENA) Conference for Rare Diseases, 17-20 April in Abu Dhabi and the Arab Society of Paediatric Endocrinology and Diabetes Conference (ASPED) held on 26 and 27 September in Dubai. In recent years, we have been working to engage with professionals throughout the MENA region in an effort to better understand the experiences and needs of people with PWS and the professionals who support them.

Presentations at these events were delivered by Professor Tony Holland and Dr Charlotte Höybye. In addition, while managing the IPWSO booth at the MENA conference, Tony also presented a poster entitled *Reducing global health inequalities for the rare neurodevelopmental condition, Prader-Willi Syndrome (PWS): the role of the International PWS Organisation*. We were delighted that this work was recognised as one of the top five posters in its awards category!



Drs Charlotte Höybye and Constanze Lämmer (CSAB) along with Drs Menbere Kahssay and Renson Mukhwana, Aga Khan University Hospital, Nairobi, Kenya, presented at the Kenyan Paediatric Association Annual Scientific Conference, 8-11 April 2025, Mombasa, Kenya. A dedicated session on PWS significantly raised awareness and knowledge of the syndrome and the case studies highlighted the diagnostic challenges and regional differences in treatment management.



Margaret Walker, CEO, Drs Susanne Blichfeldt and Charlotte Høybye (CSAB) attended the joint meeting of the European Society for Paediatric Endocrinology (ESPE) and the European Society of Endocrinology (ESE), 10-13 May 2025 in Copenhagen, Denmark. This is a major event in the clinical and academic calendar for endocrinologists and was a particularly significant meeting as it represented the first-ever joint meeting of these two prominent societies. Despite its European designation, the congress attracted participants from around the globe including delegates from the Middle East, Africa, USA, Japan, Australia and New Zealand. As part of the programme, IPWSO delivered a 30-minute presentation during the Patient Voices Session and Drs Blichfeldt and Høybye presented on PWS with a focus on genetics, endocrinology and clinical manifestations.

In collaboration with colleagues from PWS Vereinigung Deutschland and with Dr Stefani Didt, Katholische Jugendfürsorge der Diözese, Augsburg, we were proud to host our booth at the 16th Congress of the European Paediatric Neurology Society Conference (EPNS) in Munich, Germany from 8-14 July. We had the pleasure of engaging with delegates from Türkiye, Iraq, Palestine, Croatia, Moldova, the Philippines, Ukraine, North Macedonia, Kazakhstan, Armenia and many local specialists.

We were delighted to round off the year with a plenary lecture presented by Dr Susanne Blichfeldt, entitled *Neonatal Hypotonia: Clinical Features Seen in PWS That Can Help Differentiate It from Other Congenital Disorders with Similar Symptoms*, at the Global Newborn Society Inaugural Conference, held in Stockholm, Sweden, from 2-4 November 2025. Our thanks to Dr Akhil Maheshwari, founder of the Global Newborn Society for facilitating this opportunity.

Dr Blichfeldt said:



The programme was wide-ranging and stimulating, featuring cutting edge discussions on newborn health, early diagnosis and innovative care practices and our presence sets a strong foundation for future collaboration within this growing global network.

Our educational outreach activities were made possible in 2025 by the generous support of the healthcare industry and Friends of IPWSO (USA), without whose support we could not have extended our reach, shared vital knowledge, or connected with so many professionals across diverse regions of the world – a huge shout out to them for all their support this year!

United in Hope: International PWS Conference: Nora McNairney

The 12th International Prader-Willi Syndrome Organisation Conference: United in Hope (UIH 2025) was held from 24–28 June 2025 in Phoenix, Arizona. This was a historic milestone – for the first time ever the three leading PWS organisations - the Prader-Willi Syndrome Association | USA (PWSA | USA), the Foundation for Prader-Willi Research (FPWR) and IPWSO came together to host a united global event. Together we welcomed a record-breaking 1,330 delegates which is the largest turnout in each organisation's history.

The Programme Committees deserve huge credit for delivering cutting-edge, vibrant, and wide-ranging programmes, featuring expert speakers and dynamic formats that unquestionably invited audience participation. Delegate testimonials speak volumes about the exceptional quality of the content and of the general conference logistics, and remarkably, even with such large numbers, the warm sense of family and community never faded. As summed up by Kaina W:



It felt like a big family reunion, getting to see and catch up with our PWS families.

IPWSO was pleased to receive dedicated funding from Friends of IPWSO (USA), which enabled us to provide financial support to delegates from Argentina, Bulgaria, Brazil, China, Colombia, Egypt, Hungary, Kenya, Malaysia, México and Nigeria. This support ensured the meaningful participation of colleagues from a wide range of geographical and cultural backgrounds who might otherwise have been unable to attend.

The contributions of these delegates, particularly during the dedicated PWS Around the World session, were invaluable. Their shared experiences, insights and perspectives enriched discussions, broadened understanding, and highlighted both the common challenges and diverse approaches to Prader-Willi syndrome across different regions.

SUMMARY



1,330

Total Number of Registrants



CLINICAL & SCIENTIFIC PROGRAM

Number of Sessions Offered: 60

Oral Abstracts: 32

Lightning Talks: 20

Poster Abstracts: 95

Number of Speakers: 61

NUMBER OF ATTENDEES BY EVENT



Clinical & Scientific Program

413



Professional Providers Program

161



PROFESSIONAL PROVIDERS PROGRAM

Number of Sessions Offered: 17

Number of Speakers: 19

Poster Abstracts: 3



Adults with PWS Program

59



Family Program

823



FAMILY PROGRAM

Number of Sessions Offered: 24

Number of Speakers: 67



SYS Program

22



PWS Camps

187



50th Birthday Party

720



Night Under the Stars Gala

73

WHERE IN THE WORLD DID ATTENDEES TRAVEL FROM?

We Welcomed 146 International Attendees!

- Argentina
- Austria
- Australia
- Belgium
- Brazil
- Bulgaria
- Canada
- China
- Congo (Democratic Republic)
- Costa Rica
- Egypt
- Dominican Republic
- France
- Germany
- Greece
- Hungary
- Ireland
- Japan
- Kenya
- Malaysia
- Mexico
- Netherlands
- Nigeria
- Norway
- Sweden
- Switzerland
- Taiwan
- United Kingdom
- USA

We are indebted to all our sponsors – the healthcare industry, charitable organisations, PWSA | USA chapters, professional providers, individual donors and Friends of IPWSO (USA). We are also indebted to the many individuals who gave generously of their time and expertise and chaired meetings, gave presentations, developed programmes, provided guidance, managed our IPWSO stand, and helped navigate the delivery of the event We are very grateful to the Boards and staff of PWSA | USA and FPWR - Stacy Ward, Theresa Strong and Susan Hedstrom - as well as Marguerite Hughes, who as outgoing CEO remained onboard to see this project through to its successful conclusion.

For IPWSO, creating a legacy from its conferences is essential - not only to justify the significant investment of limited resources, but to ensure that long after the final session has ended, PWS interests have been advanced, future leaders have been inspired, continuity has been secured, and our global community has been strengthened.

This year, the Clinical and Scientific Programme Committee, under the leadership of Dr Dan Driscoll, introduced the inaugural Outstanding Young Investigator Awards and also a very well received lightning oral / poster session. As Dr Driscoll now steps away after many years at the helm of this vital strand of IPWSO's work, it is fitting to honour his outstanding contribution - his influence will endure through his vision, the ideas he has championed and the high standards he has established.

The same may be said of Tony Holland, Marguerite Hughes, Verena Gutmann, and Norbert Hôdebeck-Stuntebeck, each of whom has played a pivotal role in shaping our international conferences in the UK, Canada, Cuba, Ireland and this most recent event. Their leadership, vision, and commitment have left an enduring mark, one that will continue to guide and inspire future generations within the IPWSO community.

We now look forward to working with colleagues in SPW Brasil to deliver our 13th International PWS Conference in 2028, set against the beautiful backdrop of Foz do Iguaçu!



A small selection of photographs from the conference is included here. Additional images are available on [our website](#) and on the [PWSA | USA website](#). Recordings from the Family Programme (main ballroom sessions) can also be viewed via the [PWSA | USA YouTube channel](#).



Online events: Karin Clarke

In 2025 IPWSO held several successful online events. Video presentations of the talks can be found on IPWSO's [YouTube channel](#)

The Caregivers' Forum:

In 2025, IPWSO piloted the Caregivers' Forum as a new initiative - a virtual space for professional PWS caregivers worldwide to connect and collaborate. Three meetings were held: Grief in a PWS Residential Setting on 23 January, Embracing Cultural Diversity in Residential Care on 22 May and How to establish a PWS residential home on 25 September. Feedback from participants has been very positive, and the forum now has over 200 caregivers signed up to take part.

Research and Clinical Trials Update Meeting:

Researchers, pharmaceuticals and families came together to discuss research into PWS on 11 September. Representatives from Palobiofarma, Acadia Pharmaceuticals, Aardvark Therapeutics, and Soleno Therapeutics presented. The meeting was attended by over 100 people and feedback was positive.

Family Meeting:

Starting Good Habits Early - Information for Young PWS Families was a well-attended meeting held on 28 October, attracting 173 participants. The use of simultaneous Spanish translation significantly increased accessibility and contributed to a wider audience. The programme featured three informative and inspiring presentations delivered by a clinician and parents, offering practical insight and shared experience for families of young people with PWS.



Dr Kemi Ashubu, the paediatric endocrinologist in Ibadan managing the first known genetically confirmed case of PWS in Nigeria (made possible by the IPWSO free screening initiative in Italy) facilitated the patient's mother's participation in the last Family Seminar. The mother's literacy level is low, but she was able to join in the meeting in the doctor's office, had information translated and even asked a question which was satisfactorily answered and improving her confidence in caring for her child with PWS.

Email feedback received from Dr Elizabeth Oyenusi

Summit Meeting:

Global Perspectives on Stigma: Understanding Intellectual Disability and PWS Across Cultures was held on 12 November and was attended by 75 participants. The meeting featured four high-quality presentations from speakers based in South Africa, Colombia, Qatar and India, offering diverse cultural perspectives. The session provided attendees with practical ideas for reducing stigma and, as noted by one participant, fostered a strong sense of belonging through the sharing of lived experiences.



Thank you very much for organizing these meetings it's clear that we all face similar challenges around the world, and it really helps us to feel that we're not alone.

ML, from Slovakia

For more information, visit: www.ipwso.org/news-events/

Policy: Margaret Walker

Our policy and research work continues to influence real-world change, as reflected in this recent message from New Zealand, where IPWSO's evidence has directly informed a proposal for improved PWS-specific residential services.



I thought you might (also) be interested in a proposal I have just submitted to the commissioning team for disability services stressing the need for more PWS specific residential services in New Zealand. I used extracts from IPWSO's recently published research on PWS specific care homes, so I want to thank you for your work on this. I'm not sure if the proposal will trigger any action - there have been lots of funding cutbacks recently and I'm still waiting for a response.... Many thanks,

Jo Davies, CEO / Operations Manager,
Prader-Willi Syndrome Association (NZ) Inc.

We were pleased to have contributed to the International Alliance of Patients' Organisation Global Patient Charter on Social Participation which was launched in November 2025. The Charter sets out clear standards for what meaningful participation should look like, ensuring that patients, families, and communities are truly involved in shaping health policies and health-system decisions. It supports the global movement to embed social participation in national health strategies, following recent World Health Assembly commitments. The Charter is supported by an Initial Guidance Document that will help patient organisations around the world apply its principles in practical ways. We are honoured to have played a role in shaping this important work, which reflects the shared belief that health systems are stronger when patient voices are heard.

In June 2025, IPWSO was offered observer status at the European Medicines Agency (EMA)'s Patients and Consumers Working Party (PCWP) for the 2025-2028 mandate. This provides IPWSO with the opportunity to further engage with EMA and with the other members of the PCWP, by observing the meetings and having a closer insight on the topics being discussed throughout the year. In July, IPWSO's CEO, Margaret Walker, attended the EMA Annual Training meeting which provided an opportunity to introduce IPWSO and PWS to the other participating associations. Additionally, Margaret attended two meetings of the PCWP as well as a joint meeting of the PCWP and Healthcare Professionals Working Party (HCPWP).

Research: Prof Tony Holland

Presentations at the United in Hope: International PWS Conference were a high point of the year and illustrated the breadth and depth of research into PWS being undertaken across the world. This is undoubtedly an exciting time as there is the real possibility of new treatments, particularly for hyperphagia. The first such treatment marketed as VYKAT XR was approved by the U.S. Food and Drug Administration (FDA) in 2025 and is now potentially available to people with PWS in the USA. However, this has highlighted the fact that such treatments are unlikely to be universally available either because of cost or because of the complexity of gaining approval globally.

We held our third Research and Clinical Trials meeting on 11 September to inform families and clinicians about other trials planned or taking place and the prospects for future treatments. Our aim through these meetings is to build a global community that can advocate for new treatments as they become available. With this in mind, on 28 April we held a virtual meeting dedicated to better understanding how global access to treatments might be achieved. Talks from Professor Steffen Thirstrup, Chief Medical Officer at the European Medicines Agency, Charles Gore, Executive Director of the Medicines Patent Pool, and Dr. Anish Bhatnagar, Chief Executive Officer of Soleno Therapeutics highlighted the processes and challenges expanding access beyond the USA and Europe and other high resource countries such as Australia.

We continue to facilitate research focussing on global issues. Our study on the global availability of growth hormone is being revised at present, but we hope it will be published in 2026. The report of the IPWSO Mental Health Network: *Improving mental health and well-being for people with Prader-Willi syndrome*, was launched at our United in Hope: International PWS Conference and we are hoping that papers from this report will be published in peer reviewed journals. The [full report](#) is available on our website. These initiatives aim to facilitate understanding of the needs of people with PWS so as to ensure equal access to information, treatment and support across the world.

The work of this committee is still developing with plans for establishing and maintaining a global PWS research community and supporting further research that focuses on global issues.

People with PWS Committee: Gary Brennan and Shelly Cordner

The IPWSO People with PWS Committee supports individuals with PWS to advocate for themselves, ensuring their voices are recognised, valued, and included. Working directly with people with PWS, the committee creates opportunities for connection, mutual support, and meaningful dialogue with professionals around quality of life and wellbeing.

In the first half of the year, the committee published "*With Us, Not About Us*," a practical guide on developing and supporting groups for people with PWS, drawing on international collaboration and lived experience. These groups help build confidence, friendships, and a sense of belonging, while empowering individuals to participate in decisions and influence the support and services that affect their lives.

A highlight of the year was the active participation of people with PWS at the United in Hope: International PWS Conference in June. Alongside the outstanding work of the conference organisers in designing dedicated programmes for adults and children with PWS, our committee contributed by supporting a welcome video from a PWS group in Bavaria, and the delivery of a workshop on Promoting and Fostering-Self Advocacy. Participants were treated to powerful presentations on video from Ken Yap, Malaysia and David West, Australia, and inspiring in-person talks from Brooke Fuller and James Towle, USA. Brooke reminded us that she, and everyone with PWS, has a voice, and that we can play a role in helping others find and use theirs. James encouraged participants to be courageous and open to new experiences with the simple but compelling message:



If you want to try something new, just do it.

We would like to thank committee members Norbert Hödebeck-Stuntebeck, Georgina Loughnan, Svetlana Labun, James O'Brien, Hubert Soyer, Kate Woodcock, and Lantz Yap for their time, expertise, and commitment to this important work. In 2026 the committee will survey all IPWSO members to understand how they currently run groups with people with PWS, and to support any countries wishing to establish or strengthen their own programmes. These initiatives will help ensure that more people with PWS can take part in meaningful activities, build supportive networks, and access structured opportunities that promote learning, independence, and a richer quality of life.

International advocacy: Margaret Walker

In 2025 IPWSO was a member of or formally affiliated with the following international organisations:

- European Medicines Agency (EMA)
- 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 2025:

1. IPWSO attended the various Rare Disease International (RDI) Member sessions relating to the World Health Assembly (WHA) Resolution on Rare Diseases, as well as the RDI International Federations Meeting
2. IPWSO continued to engage with the GloBE-Reg PAG
3. Margaret Walker attended a European Medicines Agency (EMA) training day, as well as attending various EMA open meetings and the Patient and Consumers Working Party (PCWP) meetings as an observer
4. We strengthened our close links to ESE by becoming an ESE Patient Advisory Group (PAG) Representative
5. Via our social media activities, we joined in on the celebrations for Rare Disease Day and World Hormone Day

Genetic screening: Margaret Walker

In the 23rd year of offering our free genetic screening service we continue to collaborate with the Baschirotto Institute for Rare Diseases (BIRD) which kindly subsidises our service. In 2025, the Institute, which is based in Vicenza, Italy, carried out 13 tests on behalf of IPWSO. The total number of tests carried out since the inception of IPWSO's screening service in 2003 is 610, and samples from more than 50 countries have now been tested.

One highlight of 2025 was validation of what is thought to be the first genetically confirmed case of PWS reported in Nigeria, a finding that was outlined in a manuscript published in the Nigerian Medical Journal. The authors highlighted the importance of timely diagnosis and support also kindly acknowledged IPWSO for support via its free genetic screening service.

Once again, tests conducted on behalf of IPWSO in 2025 were kindly sponsored by support received from OT4B and donations made by members of the public.

As always, the success of our diagnostic testing programme continues to rely on doctors and families knowing about this service. In 2025, we continued to use various communication channels to raise awareness of the service, in addition to promoting it at relevant conferences and meetings, and in our email exchanges with families and healthcare professionals worldwide.

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 (www.ipwso.org/how-we-can-help/free-genetic-screening).

Advice service: Margaret Walker

This year IPWSO received over 100 queries from individuals in over 40 countries.

Through our “Ask a Professional” service, we received 14 specific medical queries. These mainly related to weight gain/obesity, access to growth hormone and behavioural issues.

As well as responding to medical queries, IPWSO staff and volunteers also answered other questions, ranging from requests for signposting to services available in different countries, to support for students and opportunities for involvement in local capacity building, as well as questions about United in Hope, our various meetings, and grant opportunities.

Most of the requests we receive are from countries where there is no PWS association, and we are grateful to be able to support these families who need us most. When questions and requests come from countries where there is a PWS association, we encourage the families to join their national associations and to become involved in their activities, in addition to joining IPWSO Family Meetings.

Many people around the world continue to live without access to medical and professional support but by sharing information and providing guidance, IPWSO continues to make a difference to people and families living with PWS.

IPWSO is extremely grateful to the volunteers who support our advice service, in particular to our Clinical and Scientific Advisory Board (CSAB) and especially Dan Driscoll MD, PhD, and Dr Charlotte Höybye, who, working together with Susanne Blichfeldt MD, continued to provide practical and insightful guidance.

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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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