



IPWSO

International
Prader-Willi Syndrome
Organisation



**20
22**

ANNUAL REPORT

www.ipwso.org

Registered as a charity in England & Wales, charity no. 1182873

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Our 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.

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.

President's report: Prof Tony Holland

Last year was a year of transition from the more extreme restrictions of the pandemic to being able to meet freely but with a certain apprehension. During 2022 the core activity of IPWSO continued to be the support of people with PWS and their families wherever they live in the world. This was through providing access to a genetic diagnosis, and by making information available to families, health professionals, professional care providers and to our membership. During the year we completed our four ECHO programmes, established our Mental Health Network, and with the support of many care providers in different countries we undertook a study of services that support adults with PWS. This year we were very pleased to welcome PWS China and PWS Bolivia as new members, bringing our membership to 44 national associations. My congratulations also to PWSA UK, who celebrated their 40th anniversary this year. We are continuing to foster our links in other countries with a focus on Africa with support from the African Society for Paediatric and Adolescent Endocrinology.

The highlight for 2022 was holding our international conference in person at the University of Limerick in Ireland. It was truly a global meeting with over 500 attendees from 38 countries. These conferences, which are held every three years, are always special but this one especially so, occurring after three years of COVID-19 lockdown. My particular thanks to PWSA Ireland for being such wonderful co-hosts. A new addition at this international meeting was a one-day interdisciplinary conference aimed at clinicians, those disciplines allied to medicine, and teachers. This was very well received, as were the clinical and scientific, parents', and professional providers' and caregivers' conferences, and the conference for adults with PWS and the children's programme. Thanks go to all of you who were able to attend and to the many parents, people with PWS, care providers, researchers and clinicians who submitted papers and who gave talks and took part in discussions. Many also made brief videos for us that are now available on our [website](#).

IPWSO could not do its work without the financial support it receives from our members, individual donors, pharmaceutical companies and other organisations, in particular Friends of IPWSO (USA). Again this year a particular thank you goes to Jean Phillips-Martinsson, our Honorary President, for her on-going and very generous support.

IPWSO is led by our CEO, Marguerite Hughes, together with the staff, Agnes Hocht, Nora McNairney, and Shelly Cordner. I am very grateful for all that they do and for their support and commitment to IPWSO. A special thank you to Nora as she was the person behind the organisation of the conference, a challenging task wonderfully executed. Finally, my thanks to the Trustees, the Chairs and Members of our various Committees, and our Advisers and other volunteers for their commitment, guidance and hard work. There is much more still to do to reduce global inequalities and improve the life-experiences of people with PWS and their families but this is a time of hope as our understanding of PWS increases, new treatments are being tried, and there is a strong international PWS community in place to provide support.

Chief Executive Officer's report: Marguerite Hughes

As another busy year ends it feels timely to once again reflect on the progress we are making. To what extent in 2022 did we fulfil our mission of uniting the global PWS community to collectively find solutions to the challenges of the syndrome and supporting and advocating for people with PWS and their families, PWS associations, and professionals who work with people with PWS? Before answering this question, it is helpful to recognise that our work comprises two elements: the visible help we provide by means including information resources, free diagnostic testing, support for conferences and workshops, and research outputs; and the less visible infrastructural developments that facilitate the growth of our existing projects and allow us to sustainably develop new initiatives.

2022 was the third full year that IPWSO operated as a registered charity in England and Wales. Our income grew year on year during this period allowing us to develop new projects and grow existing ones. It has been gratifying to observe the impact of these projects, which are described throughout this report. IPWSO's growth has brought with it a need to further develop our systems. In 2022, for example, we adopted Customer Relationship Management (CRM) software to facilitate more efficient and sustainable management of our data.

Of course, in 2022 our largest and most visible project was the 11th IPWSO Conference hosted in collaboration with the Prader-Willi Syndrome Association of Ireland (PWSAI). After prolonged worry about whether the conference would need to be postponed due to COVID-19, It was a joy to see the conference proceed and to engage with so many of our supporters and members in Limerick. For an organisation with the equivalent of less than 3 fulltime staff members, the organisation of each IPWSO Conference brings significant challenges. The 11th IPWSO Conference simply would not have been possible without the tremendous support provided by PWSAI and our large international community of committed volunteers.



Once again, the hours committed by volunteers to IPWSO far outstripped the number of hours worked by paid staff members.

Of course the IPWSO Conference, and all of our activities, also rely on donations and sponsorship. Once again we were very grateful to receive generous contributions from our donors.

Buoyed by our experience in Ireland we are starting 2023 full of ambition for IPWSO and for people with PWS and their families around the world. On a personal note, I feel privileged to work alongside such skilled and committed staff members, trustees, advisers and supporters.

YEAR IN REVIEW

2022



**206 ECHO
participants
recruited from
49 countries**

**14 diagnostic
tests provided,
a total of 566
since 2003**

**Advice line
enquiries
received from
36 countries**

**372.5 hours of
our videos
watched**

**45 members
and contacts
in over 100
countries**

**11,268
volunteer
hours worked**

**43,204 website
visitors**

**11 new videos
recorded**

**More
resources
translated,
into a total of
21 languages**



FINANCIAL INFORMATION

Treasurer's Report: Craig Moore

I am very pleased as the new IPWSO Treasurer to present the report for 2022, and at the outset I want to thank my predecessor, Marcello Schutzer, for all his expertise and direction in ensuring good governance of our finances over the last number of years. Marcello demitted office in July 2022 and at that time we were pleased to welcome two new members to the Finance and Fundraising Committee (FFC), Tünde Liplin and Michelle Torbert; together with Joan Gardner, Marguerite Hughes and Nora McNairney we hope to build on Marcello's good work and that of our predecessors and so consolidate and strengthen IPWSO's financial position going forward.

The Finance and Fundraising Committee (FFC) met on nine occasions over the year. We worked to align our functional and reporting currencies so that we now present our accounts both internally and externally in USD. The GBP figures shown in the financial statements for 2021 are now restated in the Trustees' Report and Financial Statements for the Year Ended 31 December 2022 in USD, for comparison purposes. 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 defined by our Board of Trustees. Our restated opening balance on 1st January 2022 was \$331,914 and the closing balance on 31st December was \$407,241. Full details of our finances can be found in the accompany financial statements.

We are currently restructuring FFC to better delineate its functions and will form two separate committees in 2023 - a Fundraising Committee and a Finance Committee. We have also formed a new committee which will oversee investments. Our stronger year-end financial position has allowed us to recommend the extension of staff contracts until mid-2025. These exciting developments will assist IPWSO's longer term planning.

The financial risks associated with the 11th International Prader-Willi Syndrome Organisation Conference (IPWSO 2022) predominated our thinking in the earlier part of the year as we emerged slowly from the pandemic and debated the conference's financial viability. I am very pleased to report that IPWSO 2022 was an enormous success both financially and in furthering IPWSO's mission to the global PWS community. We are very grateful to Novo Nordisk, whose flexibility permitted us to re-purpose unspent monies provided for a separate project in 2021 and we are indebted to the many industry partners, caregiving organisations, and others who supported IPWSO 2022. The Prader-Willi Syndrome Association Ireland worked exceptionally hard to fundraise and their efforts have made a significant contribution to the healthy final conference financial outcome.

Thank you to everyone who provided travel scholarships. Landsforeningen for Prader-Willis Syndrom, (Norway PWS Association) funded a Paediatric Endocrinologist from Bulgaria and Friends of IPWSO (USA) provided travel and strategic grants to 13 delegates - medical professionals, researchers and parents, hailing from Argentina, Brazil,

Ecuador, Egypt, Georgia, Hungary, Kenya, Peru, Romania, Slovakia, South Africa and the UK.

The generosity of Friends of IPWSO (USA) over the year has supported multiple activities including the delivery of conference and workshops in Hungary and Mexico, project management costs to support IPWSO's Mental Health Network, the ECHO® programme for Professional Providers and Caregivers, the development of a Customer Relationship Management system and interpretation and translation, into multiple languages, of some key educational resources.

Much effort is expended on fundraising. Applying for grants is a time-consuming activity and Marguerite Hughes and her team are to be commended on their efforts and success. An anonymous donor enabled a successful matched funding campaign which raised \$14,000 – a huge thank you for such generosity! We received a Rare Patient Health Equity Impact grant from Global Genes which permitted us to produce a wide range of short films, again in multiple languages. Residual funds from a Pfizer educational grant, received in 2020, provided support for a medical student to present at IPWSO 2022 on our Leadership ECHO® project, and also enabled us to finance the publication of a paper in the Orphanet Journal of Rare Diseases. OT4B provided funds to support our diagnostic testing service and individual donations and membership subscriptions continue to help fund IPWSO's general expenditure and office running costs.

2022 Funding Sources at a Glance

In 2022 IPWSO received funding from the following sources:

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

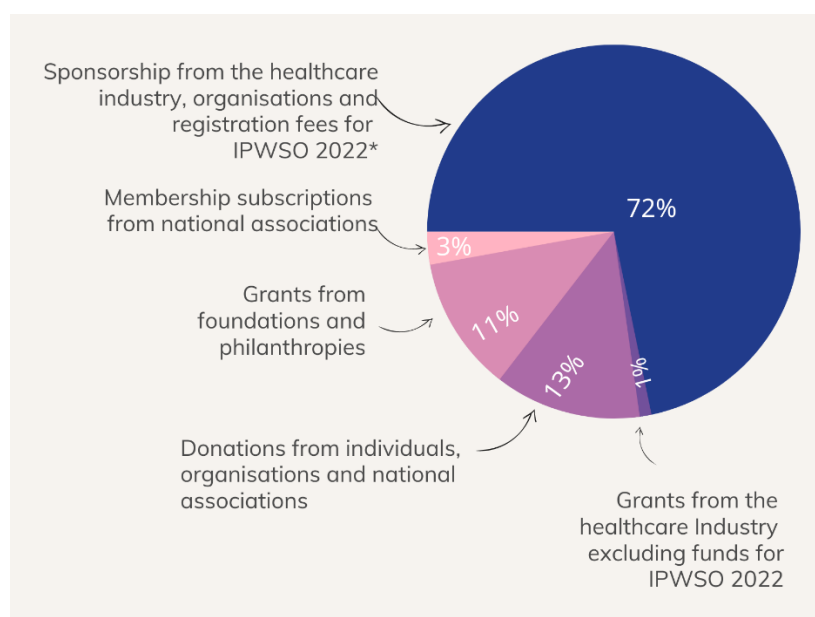
The following pharmaceutical industry partners provided support to IPWSO in 2022¹:

Saniona
Solenio
OT4B
EPM
Aardvark
ConSynance
Gedeon Richter

¹We received sponsorship for IPWSO 2022 from Radius and Novo Nordisk in 2021.

The percentage of IPWSO's income provided by industry partners in 2022 was 13%. (51% in 2021). The largest single industry donor in 2022 was Saniona.

Breakdown of IPWSO's Income in 2022



*IPWSO 2022 Breakdown: 51% registration fees, 33% Other donations and sponsorship, 16% pharmaceutical industry. This excludes major sponsorship received in 2021 from Novo Nordisk and Radius.

Bank Balances

At the end of 2022 we maintained the following balances in our accounts:

USD: \$52,626

GBP: £93,357

EURO: €229,239

Acknowledgements

Without the continuous commitment of all our benefactors, Friends of IPWSO (USA), member associations, individual donors, industry partners and philanthropic organisations, IPWSO could not fulfil its obligations to the global PWS community – thank you all, and a very special thanks to Jean Phillips-Martinsson, our Honorary President, whose generosity has been unwavering.

Thank you to Prof Tony Holland and Marguerite Hughes for their leadership, guidance and commitment. Thank you to Nora McNairney for her operational management of our finances, and also to my colleagues on the Finance Committee for all their work and support in 2022.

Major donors and sponsors

Jean Phillips-Martinsson

Friends of IPWSO (USA)

Novo Nordisk

Radius

Foundation for Prader-Willi Research

Global Genes

Resilience Healthcare

Saniona

Soleno

PWSA | USA

OT4B

EPM

Aardvark

Prader-Willi-Syndrom Vereinigung Schweiz (Switzerland)

Consynance

PWS Care Ltd

Landsforeningen for Prader-Willis syndrom (Norway)

Prader-Willi Vlaanderen vzw (Belgium)

Gedeon Richter

Digital Lift

IPWSO is grateful to Friends of IPWSO (USA) for their regular support to help us improve the lives of people with Prader-Willi syndrome and inform those who support them. Without generous grants from Friends of IPWSO (USA) none of the projects listed here would have been possible in 2022.

IPWSO MENTAL HEALTH NETWORK

Connects mental health professionals who support people with PWS or have a research interest in PWS along with professional and family carers to reflect on existing knowledge and research, identify priorities for new research, and identify ways to undertake this research.

CAREGIVERS' ECHO

Aimed at Caregivers and Providers who are in contact with people with PWS in an all-day setting. The goal of the ECHO was to learn together, examine and improve methods, and develop solutions for challenges that can arise when working with people with PWS.

CONFERENCE SCHOLARSHIPS

With generous support from Friends of IPWSO, IPWSO was delighted to offer travel scholarships and strategic grant funding to 13 individuals to enable their attendance at IPWSO 2022.

CRM SYSTEM

Integration of a Customer Relationship Management system (CRM) to keep track of IPWSO's contacts and to manage and record interactions.

TRANSLATIONS INTO MANDARIN

Translation into Mandarin of the Consensus Documents and one-page guide developed by our Clinical and Scientific Advisory Board.

SUPPORT FOR CONFERENCE AND WORKSHOPS

Funding from Friends of IPWSO enabled us to support the Mexican Association's Family Day and the Hungarian Association's Conference, both held in October 2022.

PUBLICISING DIAGNOSTIC TESTING SERVICE

Supporting the work of Associação Brasileira da Síndrome de Prader-Willi to promote the diagnostic testing service being provided in Instituto Fernandes Figueira (IFF) in Rio de Janeiro. This free PWS testing service has now been extended to the rest of Latin America.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

INDEPENDENT EXAMINER'S REPORT FOR THE YEAR ENDED 31 DECEMBER 2022

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 2022.

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 (enter body here), which is one of the listed bodies.

Your attention is drawn to the fact that the CIO has prepared the accounts in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has been withdrawn.

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

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

1. accounting records were not kept in respect of the CIO as required by section 130 of the 2011 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**INDEPENDENT EXAMINER'S REPORT (CONTINUED)
FOR THE YEAR ENDED 31 DECEMBER 2022**

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: 19 April 2023

**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 2022**

		Restricted funds 2022 \$	Unrestricted funds 2022 \$	Total funds 2022 \$	As restated Total funds 2021 \$
	Note				
INCOME FROM:					
Donations and legacies	2	136,951	41,475	178,426	99,088
Charitable activities	3	210,911	10,139	221,050	240,418
TOTAL INCOME		347,862	51,614	399,476	339,506
EXPENDITURE ON:					
Charitable activities	4	210,301	113,875	324,176	222,811
TOTAL EXPENDITURE		210,301	113,875	324,176	222,811
NET INCOME/(EXPENDITURE) BEFORE NET LOSSES ON INVESTMENTS		137,561	(62,261)	75,300	116,695
Net losses on investments		-	-	-	(863)
NET INCOME/(EXPENDITURE)		137,561	(62,261)	75,300	115,832
Transfers between funds	11	(186,320)	186,320	-	-
NET MOVEMENT IN FUNDS		(48,759)	124,059	75,300	115,832
RECONCILIATION OF FUNDS:					
Total funds brought forward		87,095	244,819	331,914	216,082
Net movement in funds		(48,759)	124,059	75,300	115,832
TOTAL FUNDS CARRIED FORWARD		38,336	368,878	407,214	331,914

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

The notes on pages 11 to 21 form part of these financial statements.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**BALANCE SHEET
AS AT 31 DECEMBER 2022**

	Note	2022 \$	As restated 2021 \$
CURRENT ASSETS			
Debtors	8	654	23,436
Cash at bank and in hand		411,626	382,557
		<u>412,280</u>	<u>405,993</u>
Creditors: amounts falling due within one year	9	(5,066)	(74,079)
NET CURRENT ASSETS		<u>407,214</u>	<u>331,914</u>
TOTAL NET ASSETS		<u><u>407,214</u></u>	<u><u>331,914</u></u>
CHARITY FUNDS			
Restricted funds	11	38,336	87,095
Unrestricted funds	11	368,878	244,819
TOTAL FUNDS		<u><u>407,214</u></u>	<u><u>331,914</u></u>

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

Craig Moore

.....
Craig Moore

Date: 04 April 2023

The notes on pages 11 to 21 form part of these financial statements.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

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.

Prior year currency restatement

In the prior year the presentational currency was GBP Pounds Sterling as the Charity is administratively UK based. The Trustees consider that the Society operates predominantly in US dollars and therefore have decided to present their accounts in that currency. As a result, the prior year comparative figures have been restated into US dollars.

1.2 GOING CONCERN

The trustees have reviewed the financial position of the charity, including the impact of Covid-19 and have a reasonable expectation that the Charity has adequate resources to continue in operational existence for the foreseeable future. Accordingly, the financial statements continue to be prepared on the going concern basis.

1.3 FUND ACCOUNTING

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

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

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022**

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.

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

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

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

1.5 EXPENDITURE

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is classified by activity.

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

All expenditure is inclusive of irrecoverable VAT.

1.6 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.

1.7 INVESTMENTS

Fixed asset investments are a form of financial instrument and are initially recognised at their transaction cost and subsequently measured at fair value at the Balance Sheet date, unless the value cannot be measured reliably in which case it is measured at cost less impairment. Investment gains and losses, whether realised or unrealised, are combined and presented as 'Gains/(Losses) on investments' in the Statement of Financial Activities.

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022**

1. ACCOUNTING POLICIES (CONTINUED)**1.8 DEBTORS**

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

1.9 CASH AT BANK AND IN HAND

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

1.10 LIABILITIES AND PROVISIONS

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

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

1.11 FINANCIAL INSTRUMENTS

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

1.12 PENSIONS

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

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022**

2. INCOME FROM DONATIONS

	Restricted funds 2022 \$	Unrestricted funds 2022 \$	Total funds 2022 \$	As restated Total funds 2021 \$
Donations	136,951	41,475	178,426	99,088
	<hr/>	<hr/>	<hr/>	<hr/>
TOTAL 2021 AS RESTATED	-	99,088	99,088	
	<hr/>	<hr/>	<hr/>	

3. INCOME FROM CHARITABLE ACTIVITIES

	Restricted funds 2022 \$	Unrestricted funds 2022 \$	Total funds 2022 \$	As restated Total funds 2021 \$
Member subscriptions	-	10,139	10,139	10,593
Grants	38,926	-	38,926	224,695
Donations	3,565	-	3,565	5,130
Conference income	168,420	-	168,420	-
	<hr/>	<hr/>	<hr/>	<hr/>
TOTAL 2022	210,911	10,139	221,050	240,418
	<hr/>	<hr/>	<hr/>	<hr/>
TOTAL 2021 AS RESTATED	229,825	10,593	240,418	
	<hr/>	<hr/>	<hr/>	

4. ANALYSIS OF EXPENDITURE BY ACTIVITIES

	Activities undertaken directly 2022 \$	Support costs 2022 \$	Total funds 2022 \$	As restated Total funds 2021 \$
Charitable expenditure	277,695	46,481	324,176	222,811
	<hr/>	<hr/>	<hr/>	<hr/>
TOTAL 2021 AS RESTATED	199,414	23,397	222,811	
	<hr/>	<hr/>	<hr/>	

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022**

4. ANALYSIS OF EXPENDITURE BY ACTIVITIES (CONTINUED)

ANALYSIS OF DIRECT COSTS

	Total funds 2022 \$	As restated Total funds 2021 \$
Staff costs	110,151	118,747
ECHO project	2,878	18,212
Conferences and events costs	142,535	44,412
Diagnostic testing	2,922	4,839
Website costs	906	9,863
Clinical Trial Consortium	1,000	981
Translations	17,303	2,360
	<u>277,695</u>	<u>199,414</u>

ANALYSIS OF SUPPORT COSTS

	Total funds 2022 \$	As restated Total funds 2021 \$
Accountancy and bookkeeping fees	10,514	8,789
Foreign currency exchange	15,141	6,264
Advertising and marketing	591	2,152
Insurance	1,386	1,583
IT software and consumables	1,362	1,153
Bank charges	1,010	1,133
Miscellaneous expenses	6,615	621
Office running costs	9,862	1,702
	<u>46,481</u>	<u>23,397</u>

5. INDEPENDENT EXAMINER'S REMUNERATION

The independent examiner's remuneration amounts to an independent examiner fee of \$1,645 (2021 - \$1,667), accountancy services of \$2,348 (2021 - \$2,380) and bookkeeping fees of \$5,414 (2021 - \$4,582).

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022**

6. STAFF COSTS AND KEY MANAGEMENT PERSONNEL

	2022	As restated 2021
	\$	\$
Wages and salaries	106,627	114,342
Social security costs	1,532	2,317
Contribution to defined contribution pension schemes	1,992	2,088
	<u>110,151</u>	<u>118,747</u>

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

	2022	2021
	No.	No.
Staff	<u>4</u>	<u>4</u>

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

The charity considers its key management personnel to be the Trustees and the CEO, Marguerite Hughes. During the year, the CEO received remuneration (comprising gross salary, employer's national insurance and employer's pension contribution) totalling \$18,678 (2021: \$20,662).

7. TRUSTEES' REMUNERATION AND EXPENSES

During the year, no Trustees received any remuneration or other benefits (2021 - \$NIL).

During the year ended 31 December 2022, expenses totalling \$2,964 were reimbursed or paid directly to 4 Trustees (2021 - no reimbursement of expenses to trustees).

8. DEBTORS

	2022	As restated 2021
	\$	\$
Trade debtors	-	23,436
Other debtors	654	-
	<u>654</u>	<u>23,436</u>

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022**

9. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022	As restated 2021
	\$	\$
Trade creditors	548	79
Other taxation and social security	-	984
Other creditors	525	409
Accruals and deferred income	3,993	72,607
	5,066	74,079

	2022	As restated 2021
	\$	\$
Deferred income at 1 January 2022	66,329	-
Resources deferred during the year	-	66,329
Amounts released from previous periods	(66,329)	-
	-	66,329

10. PRIOR YEAR ADJUSTMENTS

In the prior year the presentational currency was GBP Pounds Sterling as the Society is administratively UK based. The Trustees consider that the Society operates predominantly in US dollars and therefore have decided to present their accounts in that currency. As a result, the prior year comparative figures have been restated into US dollars. The restatement of the comparative figures is shown below.

	Closing balance	Retranslated at year end rate
	£	\$
Current assets	299,940	405,993
Current liabilities	(54,568)	(74,079)
Funds	245,372	331,914

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022**

11. STATEMENT OF FUNDS

STATEMENT OF FUNDS - CURRENT YEAR

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

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022**

11. STATEMENT OF FUNDS (CONTINUED)

STATEMENT OF FUNDS - PRIOR YEAR

	Balance at 1 January 2021 \$	As restated Income \$	As restated Expenditure \$	Transfers in/out \$	Balance at 31 December 2021 \$
UNRESTRICTED FUNDS					
General Funds	195,292	110,543	(66,304)	5,288	244,819
	<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
RESTRICTED FUNDS					
IPWSO Conference/Meeting Fund	18,627	44,234	(13,379)	-	49,482
Diagnostic Testing	1,300	9,693	(5,301)	-	5,692
ECHO Funding	-	105,102	(80,483)	(5,288)	19,331
Raising Awareness	-	4,225	(1,871)	-	2,354
Mental Health Workshop	-	10,236	-	-	10,236
IPWSO at 30	-	47,330	(47,330)	-	-
International advocacy support	-	7,457	(7,457)	-	-
Education & learning support	-	686	(686)	-	-
	<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
	19,927	228,963	(156,507)	(5,288)	87,095
	<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
TOTAL OF FUNDS	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>
	215,219	339,506	(222,811)	-	331,914

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

11. STATEMENT OF FUNDS (CONTINUED)

Conference/Meeting - this fund represents monies received from Friends of IPWSO USA to support PWS conferences and workshops around the world. Surplus 11th conference funds have been transferred to the general fund, with the balance being transferred to the Friends Meetings and Workshops fund.

Diagnostic Testing - funds from OT4B and individuals to be used for diagnostic testing.

ECHO Funding - funds received in support of various ECHO (Extension of Community Healthcare Outcomes) projects held internationally, to connect health and other providers and interested parties with specialists to facilitate learning and mentorship.

CRM system - funding towards a new customer relationship management system.

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

Friends Pakistan Conference: funding to support a conference focused on Prader-Willi syndrome to be held in Pakistan in 2023.

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

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

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

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

IPWSO at 30 - Funds received from Novo Nordisk to prepare for the next 30 years supporting people with PWS and their families. Due to the effect of the pandemic on IPWSO's services, which prevented a face-to-face event, Novo Nordisk agreed that the unspent portion of their grant could instead be used as sponsorship towards the 2022 conference.

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

International Advocacy Support - Funds were received from Saniona to support IPWSO international advocacy work.

Transfers have been made from unrestricted funds to compensate restricted funds where expenditure exceeds available restricted funds. Surplus 11th conference funds have been transferred to unrestricted funds.

The Jean Phillips-Martinsson Fund is an unrestricted fund which has not specifically been ring-fenced and was established in 2020 to support IPWSO's 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. It is envisaged that this Fund will support a wide range of IPWSO projects and strengthen IPWSO's capacity and long-term sustainability. IPWSO is very grateful to Jean Phillips-Martinsson, its founder and Honorary President, for her generosity in creating this fund in memory of her son, Anders, and husband, Sven

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022**

12. ANALYSIS OF NET ASSETS BETWEEN FUNDS

ANALYSIS OF NET ASSETS BETWEEN FUNDS - CURRENT YEAR

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

ANALYSIS OF NET ASSETS BETWEEN FUNDS - PRIOR YEAR

	As restated Restricted funds 2021 \$	As restated Unrestricted funds 2021 \$	As restated Total funds 2021 \$
Current assets	87,095	318,898	405,993
Creditors due within one year	-	(74,079)	(74,079)
TOTAL	<u>87,095</u>	<u>244,819</u>	<u>331,914</u>

13. PENSION COMMITMENTS

The CIO operates a defined contribution pension scheme. The assets of the scheme are held separately from those of the group in an independently administered fund. The pension cost charge represents contributions payable by the group to the fund and amounted to \$1,992 (2021 - \$2,088). \$403 (2021 - \$238) were payable to the fund at the balance sheet date and are included in creditors.

14. RELATED PARTY TRANSACTIONS

The International Prader-Willi Syndrome Organisation has not entered into any related party transaction during the year, nor are there any outstanding balances owing between related parties and the International Prader-Willi Syndrome Organisation at 31 December 2022.



ADVISORY BOARDS

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

Membership of CSAB

The membership of the CSAB consists of 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 the last year we added 3 new members: Doctors Max Deest from Germany; Jorgelina Stegmann from Argentina; and Li-Ping Tsai from Taiwan.

Scientific papers

A manuscript written by members of the CSAB entitled, [*"The presentation, course and outcome of COVID-19 infection in people with Prader-Willi syndrome: Unexpected findings from an international survey"*](#) was published in an Open Access Peer Review medical journal.

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

The quarterly collection of papers is available on our [website](#).

Advice

The CSAB has continued to respond to requests for advice from families around the world.

IPWSO has translated into multiple languages a [one-page document](#), edited by the CSAB, of important medical facts about PWS for families to use when seeing busy clinicians and emergency personnel. This has been posted on the web page.

IPWSO meeting in Ireland, July 2022

The CSAB organised and ran a very successful International Clinical and Scientific (C&S) meeting in Ireland in 2022. There was a total of 88 presentations on a wide variety of topics about PWS. The IPWSO C&S meeting is the premier and best attended international clinical and scientific meeting in the world for PWS.

Terms of Reference (TOR)

A TOR was developed for the CSAB.

Famcare Board: Verena Gutmann

Finally this year six Famcare members (five mothers and Georgina our most experienced PWS expert) could meet face to face at the international conference in Limerick. Only María Elvira García, the mother from Colombia could not join us on this occasion. After many hours of discussions and shared experiences via Zoom during the past months it was really a pleasure to be together!

During the conference we had the opportunity to speak with and exchange knowledge about family experiences with other parents – and again the vital importance of family support was confirmed. Knowledge is the best way to manage new and difficult situations in daily life with PWS. As well as learning factual information and techniques from the many different studies presented by PWS experts, it was so heart-warming to feel the kindred spirit of the international families and to learn from each other's real life experiences too!

As a Board of IPWSO our role is concerned with the importance of learning, discussing and reporting on all the different situations that are faced in families growing up with a child with PWS and later on with a young person and adult and their developing and changing needs.

Our latest article [*Too hot, too cold: abnormal temperature sensation*](#) is available to read on the IPWSO website and the next one: *Selecting a school environment for my child* will be available in 2023. In our articles we always seek to remember the different cultures in our PWS-world, a special challenge for us as we produce new materials.

Famcare has been publishing articles for more than 10 years now on different topics to support families in their daily lives. You can find them all on the IPWSO website. Part of our role is to oversee these materials and keep them up to date. Please do help us to share these useful materials so that other families can benefit.

We love to hear your family stories and to respond and help. Do contact us via the IPWSO office on office@ipwso.org. Finally, thank you to our newest member to enrich our Famcare team, Yvonne Rochford – a young mother from Ireland.



Professional Providers and Caregivers Board: Lynn Garrick

The Professional Providers and Caregivers Board (PPCB) was pleased to be a part of the international conference in Ireland. We had a successful programme with global participation. The conference highlighted the continued need for educated, compassionate, and person-centred support for caregivers worldwide. It is always a pleasure to see and hear about what services are currently available and what services may look like in the future. We were able to learn from experts about various topics relating to caregiving which we can take back and share with our colleagues. Coming together in person is a special event that leads to partnerships, ongoing communication, and collaboration which benefits the entire PWS community.

During 2022, the PPCB participated in the Caregivers' ECHO programme, which enabled caregivers worldwide to learn about various topics essential for care provision. This is an additional way that the PPCB helped to promote global learning and support to caregivers. Recordings of these [ECHO sessions](#) can be accessed online.

The PPCB members are working on planning for the next Caregivers' Conference, which is dedicated to expanding caregivers' knowledge worldwide. We are happy to expand the role of the caregiver delegates, who will assist the PPCB in forming global partnerships with providers to disseminate best practice so that individuals with PWS can live the most meaningful self-determined lives possible.

None of this work would be possible without the passionate, knowledgeable, and dedicated members of the PPCB. My heartfelt thanks to the current members of the PPCB: Patrice Carroll, Larry Genstil, Neil Gumley, Norbert Hödebeck-Stuntebeck, Damien Jones, Laura Keane, Jackie Mallow, Hubert Soyer and Mary K. Ziccardi.





OUR PROJECTS

Conferences and workshops: Lynn Garrick

The Conferences and Workshops committee remained active despite the ongoing limitations of in-person conferences. Despite these constraints, there have been in person conferences as well as virtual conferences which provide opportunities to reach broader audiences. We have received numerous applications for assistance to host workshops and have been able to support several successful workshops worldwide.

We look forward to supporting other countries that will be hosting virtual or in-person conferences in 2023. With the ongoing support of Friends of IPWSO (USA), we can help countries provide education and training on Prader-Willi syndrome.

Prof Tony Holland, Dr Susanne Blichfeldt and Dr Charlotte Höybye all travelled to speak at the Hungarian conference in Budapest on 7th October which was attended by 50 people, split equally between professionals and families. The event was hosted by our member association PWS Hungary led by IPWSO Board Member, Tünde Liplin and provided a great opportunity to spread knowledge and awareness about the syndrome. The focus of the programme was on general symptoms, mental and physical development, therapies and research.

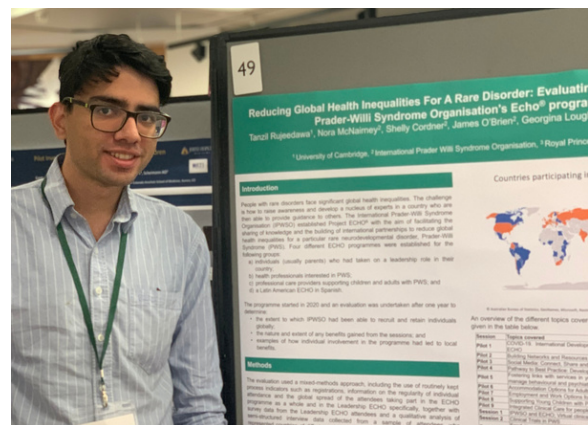
Our member association in Mexico, Fundación María José, held their 6th annual family conference on 15th October and had a successful day sharing knowledge and experiences. The event was attended by almost 200 people including people with PWS, family members, volunteers and speakers. The purpose of the day was to share information and raise awareness of the common issues affecting people with PWS. IPWSO awarded financial support for the event.

We also supported a group of professionals in Pakistan to host an in-person and online multidisciplinary day on 28th October on the management of PWS in children and adults at the Aga Khan University Hospital. IPWSO provided a series of pre-recorded talks which formed the basis of the day's agenda. The event had 16 participants online, and 15 in person, with the audience including paediatric endocrinologists, paediatric neurologists, paediatricians, nurses, trainees and other staff members. Many of these sessions were taken directly from the library of ECHO resources.

IPWSO 2022, IRELAND

We would like to thank our co-hosts PWSAI, our presenters, organisers, PWS associations, sponsors, delegates and everyone else who contributed to the success of the conference. **Thank you!**

- 519 delegates
- 38 countries
- 64 sessions
- 138 presenters
- 65 posters



Our 11th International Conference: Nora McNairney and the IPWSO 2022 Planning Committee

The biggest event in IPWSO's calendar is without doubt our international conference which always provides a wonderful opportunity to bring our PWS family together and IPWSO 2022, which took place in July in Limerick, Ireland, was no exception.

Even though it was set against the backdrop of COVID-19 and the world emerging from the challenges that wreaked havoc on all in-person interactions, numbers exceeded our expectation. With 519 delegates from 38 countries - from the Antipodes to the Americas, and Scandinavia to South Africa - arriving at the University of Limerick, the excitement was palpable, and it was clearly evident the value and importance that people place on in-person gatherings. Our theme ***"We're all in this together"*** was timely and resonated throughout the conference.

In the opening address to the Clinical and Scientific delegates, Deborah Barks, a parent from Switzerland, set the stage with her encouraging remarks underlining why we were all there, ***"Even when you are having the worst of days, don't give up. Remember there is a whole community out there, looking to you, and waiting for the results of your valuable research."***

Walaa Mohamed, a delegate at the Parents' Conference, recounts ***"I felt like I was among my family members, with people who understand what I feel, a society in which I am not afraid to integrate. The best part for me was meeting adult individuals with PWS. It was the first time to see and interact directly with adults living with PWS. It was an amazing experience to know what to expect in the future and know it will be amazing!"***

"[IPWSO 2022] Where links and connections are made," "I can rely on them [the clinical and scientific community] for advice. I have found friends, we help each other.", all comments from researchers and medics attending the Clinical and Scientific Conference.

Facilitating and expanding connections in our global PWS community was effectively demonstrated when Esther Maina, a Genetics Researcher from Kenya, interviewed Claire, a 16-year-old young person with PWS from Ireland, about her diagnosis, the symptoms and how PWS affects her on a day-to-day basis. The interview was shared on YouTube with Claire sending a message to Ruby from Kenya, who also has PWS and who has never encountered anyone living with the syndrome before. Esther says, ***"Sharing this video was an absolute eye-opener for Ruby and it encouraged her to enjoy life and know that there were many people in the greater world that care about her welfare and would like to establish a support network for her and her family"***.

"Eye-opening" was an adjective frequently used, describing responses to the diversity of abstracts submitted for the Clinical and Scientific Conference, and to the discussions on topics such as Independence and Restrictive Practices at the Professional Providers and Caregivers' Conference.

“Eye-opening” too was the feedback from a parent observing the Stepping UP Adults Symposium (SUAS), as she reflected on the session ‘We want to hear your voice’, and the impact it had upon her adult son, who *“bubbles with excitement and with empathy when he tells people about it ... [about] how much he learned from listening to other people with the syndrome speak about their experiences”*.

Amazingly, for the west coast of Ireland, the sun shone from arrival to departure. Our hosts and partners, Prader Willi Syndrome Association Ireland, (PWSAI) had even arranged the weather! On behalf of IPWSO we would like to formally acknowledge the essential role they played. Not only did they made a substantial financial contribution to support the conference, but also provided financial support to Irish families to enable them to attend in large numbers. The whole PWSAI Planning Committee dedicated themselves to the organisation of the Conference and were always willing to take on extra responsibilities. The success of IPWSO 2022 is due in large part to the commitment shown by Anthony Carr, Chair, Gary Brennan, National Development Manager, and the whole PWSAI team including volunteers, with whom it has been IPWSO’s pleasure and privilege to work. Anthony reported that the awareness raised about PWS in Ireland and the attention brought to the Association by the conference has had a *“multitude of positive effects”*, and we are delighted the conference achieved this impact.

We had a number of *“firsts”* in Ireland including a one-day Interdisciplinary Programme bringing together allied health professionals and educationalists interested in the holistic treatment and support of people with PWS. Everyone agreed that this additional strand is well worth repeating at future international conferences. Other *“firsts”* included a Superheroes Exhibition/Workshop delivered by Dr Sarah-Jane Judge and the team from the University of Edinburgh; a hybrid Mental Health Network Meeting; a Meet the Speaker session at the Parents’ Conference; an IPWSO 2022 Conference App; and the production of 10 short expert videos on PWS which are now on IPWSO’s [YouTube channel](#).

None of these activities would be possible without the generosity and goodwill of many individuals, member associations, sponsors and charitable contributors, and we are indebted to all for their support.

Global Genes helped fund the production of the videos. Friends of IPWSO (USA) provided grants to enable parents, researchers and medics from across the world to travel to Ireland. The associations in Switzerland, Belgium, Norway and USA all contributed, either by sponsoring or funding delegate attendance. The Foundation for Prader-Willi Research sponsored our Welcome Reception and an element of our Clinical and Scientific Conference, and Resilience and PWS Care Ltd, professional provider and caregiver organisations in Ireland and the UK respectively, provided sponsorship. Financial support from the pharmaceutical industry companies, Novo Nordisk, Radius, Saniona, Soleno, OT4B, EPM, Aardvark, Consynance, and Gedeon Richter, enabled us to greatly enhance the conference experience for everyone.

Thank you too, to our prominent experts, presenters, moderators, volunteers, staff, programme leads and committees, the University of Limerick and the Castletroy Park Hotel.

IPWSO 2022 was a huge team effort that delivered beyond our expectations. Our wonderful PWS family came together, facing down the challenges presented by COVID, and in the words of one professional delegate, provided an opportunity to ***"really get a sense of the life lived with a loved one with PWS. It's the only conference for a rare disorder where I have ever experienced that level of emotion. It was humbling and informative."***

Thank you so much to everyone involved. Our thoughts now turn to IPWSO 2025 and we look forward to sharing bid details with all our members in 2023.

Online events: James O'Brien and Shelly Cordner

The **IPWSO Caregivers' ECHO®**, aimed at Caregivers and Providers who are in contact with people with PWS in an all-day setting, concluded its current series with five sessions held in 2022. The programme is based on a tele-mentoring model designed by the ECHO Institute in the University of New Mexico. Topics included Attracting and retaining PWS Caregivers, Medical requirements for people with PWS, and Behaviour appreciation and positive reinforcement strategies.

94 individuals from 20 countries attended at least one Caregivers' ECHO session. Overall, 206 individuals from 49 countries registered to receive regular information on the Caregivers' ECHO, including access to written materials and video presentations for those not able to attend online.

We are grateful to all those subject experts who gave presentations to the Caregivers' ECHO. Very many thanks to Patrice Carroll, Lynn Garrick, Norbert Höedebeck-Stuntebeck, and Hubert Soyer who led this ECHO project and volunteered a great number of hours.

We are thankful to Friends of IPWSO (USA) for their financial support of the Caregivers' ECHO.

We were pleased to hold our first **Summit Meeting on Newborn screening (NBS) for Prader-Willi syndrome and other chromosome 15 abnormalities** on 3rd April. Summit Meetings provide an international online forum at which key issues of relevance to people with PWS and their families, and our international community, will be discussed.

Dan Driscoll, MD, PhD and IPWSO CSAB Chair, presented an "Overview of Newborn Screening (NBS) & Brief Discussion of Prader-Willi Syndrome", and Associate Professor David Godler, University of Melbourne, spoke on "Newborn screening for Prader-Willi Syndrome and other chromosome 15 abnormalities: Challenges and Opportunities". Both video presentations were made available to participants beforehand. Dorica Dan, Board of Directors, EURORDIS also presented "Newborn Screening: Harmonising approaches to NBS in EU" during the meeting.

This session discussed recent developments and ongoing research as well as practical and ethical issues concerning NBS for PWS. We were delighted to welcome 22 people from around the world to the online meeting and appreciate all participating in a dynamic discussion of the topic.

On 8th September we co-hosted a **webinar with the African Society of Paediatric and Adolescent Endocrinology (ASPAE)** to raise awareness of PWS amongst endocrinologists working in Africa. The webinar was attended by 50 people and saw presentations made by Prof Tony Holland, Dr Charlotte Höybye and Dr Engela Honey. A useful discussion was held, and we received positive feedback from participants. We are now seeking to build on this work by attending the ASPAE conference in 2023.

Policy and research: Prof Tony Holland

Once again we were involved in a range of research activities this year and as well as the projects listed below we worked with Tanzil Rujeedawa on [an analysis](#) of the efficacy of our ECHO® project, thank you to Tanzil for his time and efforts. We also worked with an intern from the London School of Economics, Vandana Venkat, who researched and wrote an insightful report titled, [*A Mother's Experience: a report on the social and psychological experiences of mothers raising children with Prader-Willi syndrome*](#).

Research on specialist services for people with PWS

With support from providers of specialist care services around the world, Brian Hughes led an IPWSO research project that examined body weight, behavioural well-being, and social contact in persons with PWS who enter full-time specialist care services.

Information collected by IPWSO was combined into a single anonymised dataset for statistical analysis. A total of 193 individuals with PWS, resident in 11 services across six countries, were represented in the dataset. Brian presented preliminary data from this study at the IPWSO Conference and expects to publish a paper based on the results in 2023. To our knowledge, this represents the largest ever study of outcomes for people with PWS who enter full-time specialist care settings.

Mental Health Network

Membership of our Mental Health Network is global, with representatives from 21 countries including parents, psychiatric, psychological and behavioural experts, together with other clinicians and health and social care professionals, all experts in the support of people with PWS.

The Network has collaborated through a series of eight 90-minute online meetings, and on 6th July 2022, held an in-person workshop in Limerick, Ireland.

With an ultimate aim of developing best practice guidance, the three main topic areas covered in a report drafted by the Network are:

1. Definitions of mental health and the terminology used to describe mental ill-health in people with PWS and the interrelationship with family health.
2. Understanding causative mechanisms for mental ill-health and the interrelationship between the vulnerability of the individual and past and present environmental circumstances.
3. Best practice in the assessment of mental ill-health and its prevention and treatment in people with PWS and the promotion of mental wellbeing.

IPWSO looks forward to publishing the Mental Health Network Report in the first half of 2023, and then to disseminating the information the Report contains to different groups such as parents, caregivers, health care providers and people with PWS.

Thank you to Friends of IPWSO (USA) for their support with this work.

COVID-19 and PWS

Prof Tony Holland and the Clinical and Scientific Advisory Board conducted a study into the effects of the COVID-19 infection on people with PWS. The results were analysed and written up by Dr Joyce Whittington at the University of Cambridge. The paper, [*The presentation, course and outcome of COVID-19 infection in people with Prader-Willi syndrome: unexpected findings from an international survey*](#), was published in the Orphanet Journal of Rare Diseases and is available to read online.

International advocacy: Marguerite Hughes

In 2022 IPWSO was a member of, or formally affiliated, with the following international organisations:

- [BOND – The International Development Network](#)
- [European Society of Endocrinology \(ESE\)](#)
- [EURORDIS](#)
- [Global Genes](#)
- [Healthcare Information for All \(HIFA\)](#)
- [International Alliance of Patients' Organizations \(IAPO\)](#)
- [International Coalition of Organizations Supporting Endocrine Patients \(ICOSEP\)](#)
- [International Collaboration on Rare Diseases and Orphan Drugs \(ICORD\)](#)
- [Prader-Willi Syndrome Clinical Trial Consortium \(PWS-CTC\)](#)
- [Rare Disease Ghana Initiative \(RDGI\)](#)
- [Rare Diseases International \(RDI\)](#)

Key IPWSO Advocacy Activities in 2022 included:

1. Rare Disease Day – we were active in sharing information and celebrating the lives of people living with rare diseases as part of this global awareness day.
2. Universal Health Coverage – we shared information in support of this campaign led by RDI.
3. Collaborative Global Network for Rare Diseases - the WHO and RDI are exploring how to establish a Collaborative Global Network for Rare Diseases (CGN4RD) that takes a structured approach of clustering rare diseases by therapeutic areas to be inclusive of all rare diseases and leave no one behind. Both Marguerite Hughes, IPWSO CEO, and Prof Tony Holland, IPWSO President, are members of the advisory panel of experts and they participated in workshops throughout 2022 designed to advance both the concept and methodological model for the CGN4RD.
4. In 2022 IPWSO became an Affiliated Member of the European Society of Endocrinology Patient Advocacy Group. We look forward to continued cooperation with the ESE on its policy and advocacy strategies.
5. IPWSO President Prof Tony Holland became a board member of the International Alliance of Patients' Organizations (IAPO).
6. IPWSO remains an active member of the PWS Clinical Trial Consortium, the annual meeting of which was hosted during the IPWSO Conference.
7. IPWSO continues to work with Global Genes and in early 2022 it became a founding member of the Global Genes Global Advocacy Alliance.

In addition to working with others on relevant shared campaigns, IPWSO also had an opportunity to disseminate information about its work and Prader-Willi syndrome in conjunction with its partner organisations. A selection of these awareness-raising activities is described below.

- We attended the online programme of the 4th Symposium on Birth Defects and Rare Diseases organised by Rare Disease Ghana Initiative on 6th May 2022.
- We worked with PWS China to organise a webinar and presented information about PWS to an audience of over 1,000 participants in May.
- In June we presented to the annual Membership Meeting of RDI on the RDI UN Resolution on Persons Living with a Rare Disease.
- Prof Tony Holland presented at the European Conference on Rare Diseases (ECRD 2022) in June on health inequalities.
- In September we hosted a webinar with the African Society for Paediatric and Adolescent Endocrinology (ASPAE), this was attended on the day by 50 people and viewed by 129 later as a recording.
- Dan Driscoll MD, PhD presented about PWS at the Fourth Latin American Symposium on Medical Genetics in September.

Diagnostic testing: Marguerite Hughes

For the 20th consecutive year we offered free diagnostic testing for PWS to families unable to access or afford testing in their own countries. This service was provided in collaboration with the Baschirotto Institute for Rare Diseases (B.I.R.D.), which is based in Vicenza, Italy.

Tests conducted on behalf of IPWSO in 2022 were paid for through generous sponsorship received from OT4B and donations made by members of the public. 14 tests were carried out in 2022.

The success of our diagnostic testing programme continues to rely on doctors and families knowing about this service. Once again in 2022 we used our newsletters, social media and website to raise awareness of the service, as well as promoting it at relevant conferences and meetings, and in individual correspondence with families and professionals worldwide.

In 2022 we were happy to learn that the free diagnostic testing service for PWS that is offered by the Instituto Fernandes Figueira in Rio de Janeiro, Brazil, is now accepting samples from countries throughout Latin America. We hope that this will help many additional families to secure timely diagnoses for their children.

More information about the services provided by B.I.R.D. and by Instituto Fernandes Figueira are [available on our website](#).

Website and Publications: François Besnier and Agnes Hctor

As a very small, yet international organisation, IPWSO has long been dependent on our online profile to reach the people who need our help. In 2022 our website helped us reach over 43,000 visitors, completing over 151,000 page views and 10,000 downloaded articles. Our average website visit time was over 2 minutes. This was our first full year operating a Google Ads Grant and that has proved an enormous benefit in signposting people to our site when they are looking for information online about PWS.

We also maintain profiles on Facebook, Instagram, Twitter, YouTube and LinkedIn where we share information about the syndrome, interact with people and direct people to our website for more in depth information.

We were delighted to receive new and updated materials written by our expert Boards as well as to receive funding to produce videos and to translate more of our materials into more languages, with a focus this year on Arabic, Mandarin and Turkish. Many thanks to Global Genes and Friends of IPWSO (USA) for their support in enabling these translations.

The Clinical and Scientific Advisory Board's one-page guide to [Important medical facts about Prader-Willi syndrome](#) has been very well received with over 2,600 views. The Board's four guides on the [Overview and Evaluation](#) of patients with PWS also remain very popular downloads.

Famcare's newest publication, [Too Hot, Too Cold](#), was published in late November and received 500 views in its first month online.

Our in-person conference provided a great opportunity to produce more video content and this resulted in a series of new videos which have been shared on [YouTube](#). We were also able to translate some of them into Mandarin and Arabic. Many thanks to our member association PWS China for distributing the videos within China on WeChat.

We were delighted to really grow our presence on YouTube this year with 6,700 views of our content, amounting to over 373 hours of viewing time. Our recent series [Prader-Willi syndrome: what you need to know](#), is certainly worth a watch whether you are new to the syndrome or looking to refresh your knowledge. Many thanks to our expert presenters and to Shelly Cordner for producing the videos.

We have a wealth of publications across our website and in 2023 we will continue to shine a light on these materials as well as adding to them. Many thanks to all our expert contributors as well as the many volunteers who review our translations.

Advice service: Agnes Hctor

This year we received enquiries from families and professionals across 36 different countries. For countries with established membership associations we were happy to signpost people to their local support. However, many families are still isolated in countries where there is no national association and we are delighted that they are able to find us online and we can help in a very meaningful way.

This year we saw more families contacting us from Arabic speaking countries including Iraq, UAE, Jordan and Kuwait. This has coincided with our development of IPWSO resources in Arabic and it has been extremely helpful to be able to direct people to high quality PWS materials in their own language.

In many countries we have seen a real disparity in access to affordable healthcare and diagnosis as well as very limited access to expertise relating to rare diseases. In these situations, we have been very grateful for our relationship with the B.I.R.D. laboratory where we fund our PWS diagnosis service, as well as our experts who are able to respond to questions about care and treatment.

Many of our enquiries this year related to diagnosis: families seeking diagnosis or struggling to come to terms with a recent diagnosis and what it might mean for their child. We also received many questions about diet and behaviour, two key areas in the management of PWS where information is so important and can make such a difference. Our experts responded to questions with sensitivity understanding how difficult it is to make changes to routines and to introduce consistency when there are so many environmental and social factors at play.

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



ABOUT US

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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 the development of a chronic feeling of hunger that results in over-eating and in severe obesity and associated health problems.

Multiple studies have shown that between 1 in 15,000 to 30,000 people in the populations studied have PWS, which occurs equally across all races and both sexes, although life-expectancy and population prevalence globally may differ depending on the availability of an early diagnosis and of information, treatments, services and supports.

IPWSO is committed to supporting all people with PWS and their families, whatever their needs, and wherever they live.

Ways to support our work

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

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