IPWSO

International
Prader-Willi Syndrome
Organisation

2021 | ANNUAL REPORT

WWW.IPWSO.ORG
REGISTERED AS A CHARITY IN ENGLAND & WALES 1182873

Annual report 2021

Vision

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

Mission

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

Contents

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

www.ipwso.org

President’s report: Tony Holland

This year we celebrated the 30th Anniversary of the foundation of IPWSO.

At a virtual meeting to mark this special occasion, we asked people from across the world to reflect back on how things had changed and to look forward to what they would want to see in the future. Whilst much has changed over the 30 years, the benefits that come with advances in diagnosis and knowledge are not universal and there remain significant global inequalities. As further advances are made these inequalities may become even more striking and for this reason IPWSO has been working with Rare Diseases International in support of their campaign to improve access to health care for people with rare disorders in general.

This and the other work IPWSO has done throughout 2021 would not be possible without the support of our association members, Trustees and other volunteers, and staff. A particular welcome to Shelly Cordner, who joined the staff group at the beginning of the year and organised the 30th Anniversary and has supported the ECHO programme and the mental health initiative.

Thank you to everyone for their hard work, enthusiasm, and commitment to the global PWS community.

We have welcomed this year the Fundación Dominicana de Sindrome Prader-Willi as a new member and have also worked closely with many other countries, who are not yet members. I would like to congratulate China for the work they have been doing, the countries that make up the Asia Pacific ring for their very successful conference, India for arranging a special day on PWS as part of a genetic conference, and also parents and professionals in some African countries for their initiatives. Many countries in Latin America have continued their mentoring scheme and Colombia hosted a conference. Other associations, such as PWSA | USA, have had virtual meetings, which have had a global reach, and FPWR and others have hosted events despite the challenges that have come with the pandemic. Congratulations to everyone.

During 2021 we have continued the ECHO programme with the addition of the Professional Caregivers ECHO. James O’Brien, Vice-President of IPWSO, instigated the ECHO programme, which has brought together communities from across the world. Tanzil Rujeedawa undertook an evaluation of the ECHO program, which indicated how well the programme had been received. The report is available on the website and a paper describing the findings has been submitted for publication. Whilst there were many countries represented in the various ECHO programs there are still parts of the world where we have been unable to identify parents or professionals able to engage.

Looking ahead, 2022 is the year of the IPWSO international conference to be held at the University of Limerick in the Republic of Ireland. This is going ahead in-person and we have an excellent line up of talks arranged. It will be very special, after two difficult years, to meet in person again.

Chief Executive Officer’s report: Marguerite Hughes

Despite the shadow cast by COVID-19, the tremendous goodwill of IPWSO’s volunteers, along with the dedication of its staff and support from donors, allowed us to mark our 30th year with an expanded offering of supports and services.

By means of four ECHO programmes, we facilitated meaningful online communities of learning for those supporting people with PWS. We continued to offer free diagnostic testing. We provided an advice line, along with financial support for conferences and workshops, and we expanded our advocacy and research programmes.

A highlight of the year was our 30th Anniversary Workshop, which brought together representatives from the global PWS community to help us plan for the coming decades. The willingness of people to participate in this event, along with the many positive messages we received, reminded us of the ambition and high expectations of our community.

While the workshop provided a welcome opportunity to reflect on and celebrate the many successes of the past 30 years, it also highlighted ongoing challenges.

Diagnostic testing and access to appropriate medical care are not universally available and outcomes for people with PWS vary dramatically.

There are still no effective treatments for many of the most debilitating features of the syndrome. Even Growth Hormone Treatment, which has been available for 20 years in some parts of the world, remains unavailable or unaffordable in others.

There is inequality in the availability of social care services with specialised options available in some parts of the world and a complete deficit of social care services in others.

IPWSO faces its own challenges too. Despite the generosity of our donors, the absence of long-term sustainable funding makes it difficult for IPWSO to initiate multi-annual projects.

COVID-19 remains an ongoing worry.

The environmental crisis highlighted at COP26 represents an existential threat to the world and brings additional responsibility on all of us to consider the impact of our work.

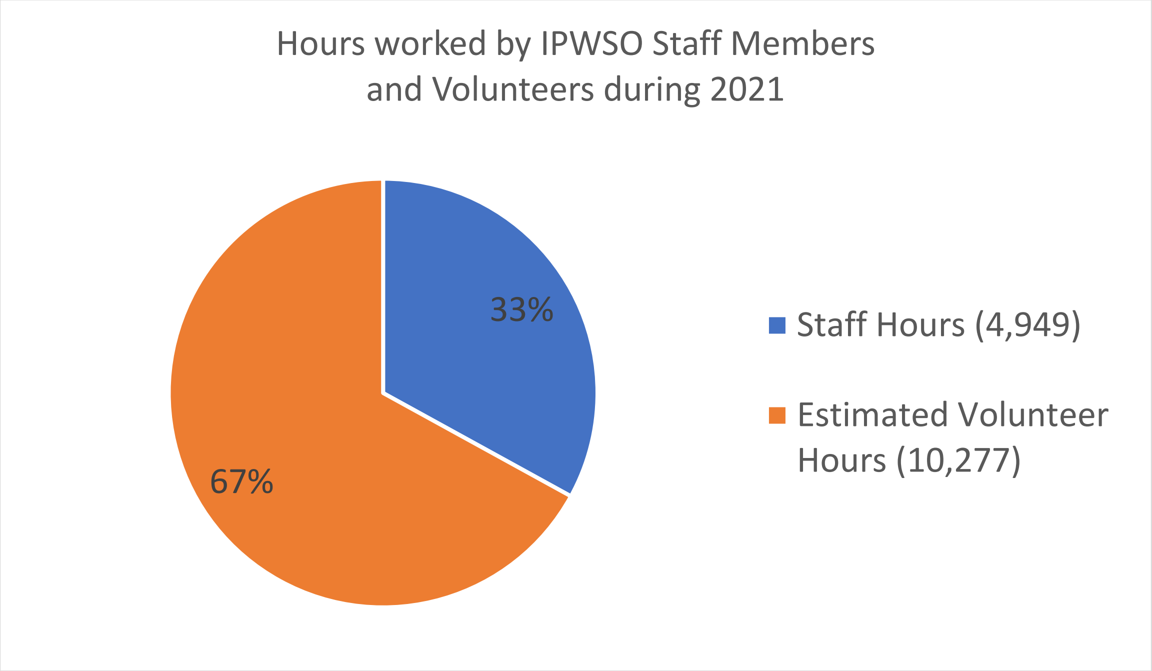
There are no easy answers to any of the challenges facing IPWSO or the global PWS community, but we can take heart from the progress made to date.

I would like to sincerely thank all of those who supported our work this year.

Thanks to our donors, in particular, Jean Phillips-Martinsson, Friends of IPWSO (USA), Pfizer, Novo Nordisk, Saniona, Resilience, OT4B and ConSynance.

Thanks to our 42 members for your guidance, commitment and financial support.

Thanks most of all to the people who make IPWSO's work possible: the small but wonderful staff team of Agnes, Nora and Shelly; our superb Board of Trustees led by our inspiring President, Tony Holland; our Clinical and Scientific Advisory Board, Professional Providers and Caregivers Board, and Family Care Board; as well as our many other volunteers and advisers. I am happy to report that once again, the time committed by volunteers to IPWSO in 2021 far outstripped the time worked by paid staff.



2021 in numbers

388
ECHO participants from 51 countries

5
Peer reviewed papers published

34,539
Visitors to our website

42
IPWSO member associations

10,277
Volunteer hours given

19
Diagnostic tests paid for by IPWSO

4
Research projects

30
Years of IPWSO celebrated

222
Hours of our videos watched on YouTube

170
Advice line inquiries from 55 countries

3
Conferences supported

10,000
Familes supported by our members

Financial information

Treasurer’s Report: Marcello Schutzer

The Fundraising and Finance Committee met on 11 occasions over the year monitoring the income and expenditure and reporting to the Trustees on a regular basis.

Despite the continuing challenges presented by the COVID pandemic, IPWSO has continued to adapt and maintain its global commitment to the PWS community and during the period a variety of activities took place in order to further the Charity’s objectives; in planning those activities the Trustees have borne in mind the Charity Commission’s guidance on public benefit.

IPWSO’s income is mainly derived from donations from individuals, philanthropic organisations, and membership subscriptions, and from grants received from corporations for specific projects. It became apparent in early 2021 that IPWSO’s annual income was likely to exceed £250,000 and as a result the Trustees decided that the accounts would be prepared using the Accruals basis. The financial statements are presented in pounds sterling which is the currency that the financial records are maintained in, however the functional currency includes £, $ and €.

The income and expenditure is detailed under restricted and unrestricted headings.

Restricted income, i.e. income from grants and donations which is associated with specific projects and initiatives, was received as follows:

Friends of IPWSO USA ($66,275) – support for various projects including Travel Fellowships and strategic support monies for our International Conference in 2022, funds for PWS awareness raising activities and developing a website search engine function, the roll-out of the Professional Providers and Caregivers ECHO®, support to create a Mental Health Network, funding to help support countries wishing to host educational conferences and workshops, and funds to support the production of publicity materials about the availability of diagnostic testing in Latin America.

Pfizer Medical Educational Grant ($95,800) - enabling us to formally launch Project ECHO®.

Novo Nordisk ($66,000) - to support our “Celebration of IPWSO at 30”, and also the International Conference.

Saniona ($7,500) - to support our work on international advocacy.

OT4B (€5,000) – support for diagnostic testing.

The University Court of the University of Edinburgh in collaboration with the University of Glasgow (£2000) – to fund a Superheroes project which will be organised in 2022.
Johnson and Johnson Medical Ltd (£499) - to help us rebrand and reformat a range of publications.

Further income was received from Resilience (Professional Care Providers in Ireland) (€10,000) to support our International Conference and other organisations indicated their willingness to provide support in 2022.

The main source of unrestricted funding came from a generous donation by Jean Phillips-Martinsson (£53,500).

2021 Funding Sources at a Glance

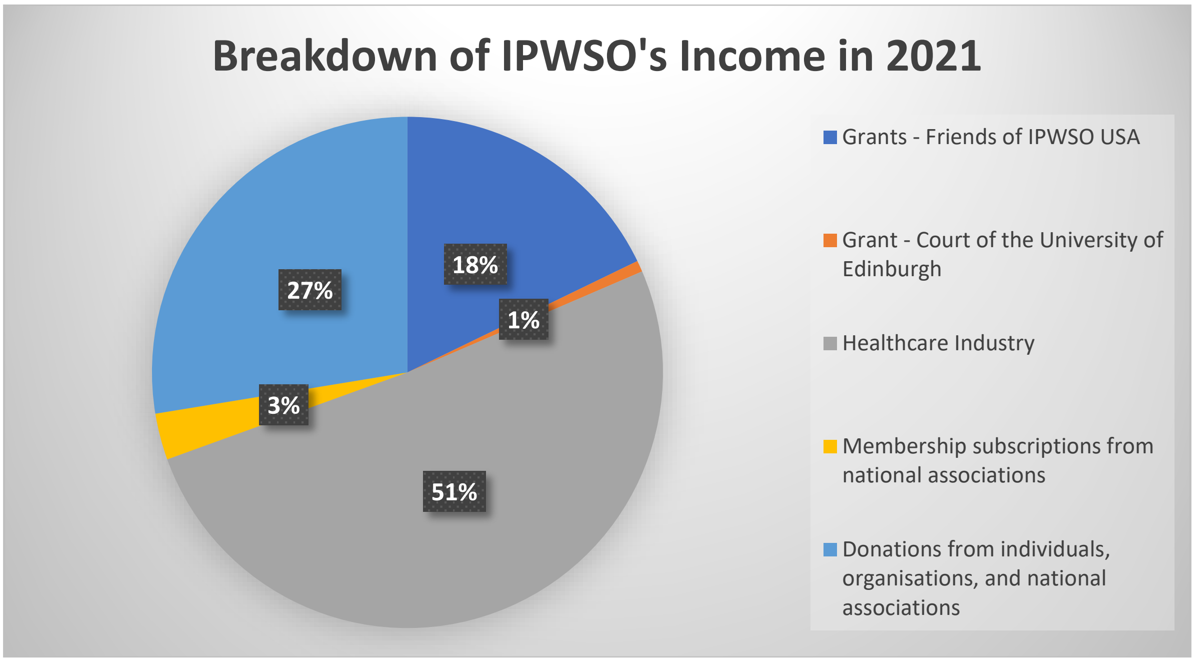
In 2021 IPWSO received funding from the following sources.

1) Healthcare industry
2) Donations from individuals, organisations, and national associations*
3) Grants from Friends of IPWSO USA
4) Membership subscriptions from national associations
5) Grant from Court of the University of Edinburgh

The following healthcare industry partners provided support to IPWSO in 2021:

1) Pfizer Inc
2) Novo Nordisk A/S
3) Saniona
4) OT4B
5) ConSynance Therapeutics
6) Johnson and Johnson

The percentage of IPWSO's income provided by industry partners in 2021 was 51%. The largest single industry donor was Pfizer, which provided 25% of IPWSO's income in 2021.



*Donations listed above included £53,500 from Jean Phillips-Martinsson.

The accompanying accounts provides details of all expenditure and is given in GBP.

Bank Balances

As at close of 2021, IPWSO had the following balances in the accounts:

- USD 205,578
- Euro 143,251
- GBP 10,246

Acknowledgements

We are indebted to Friends of IPWSO USA and their supporters for their continued generosity without which many of these initiatives would not happen.

We are also thankful to the many industry and wider sector supporters, Pfizer Inc, Novo Nordisk, Resilience, Saniona, OT4B, Johnson and Johnson, and ConSynance who have enabled ground -breaking activities, such as Project ECHO®, and our online 30th Anniversary workshop and also gave us confidence to progress our IPWSO 2022 conference.

Thank you to all our members who paid subscriptions fees and very many thanks to everyone who contributed with voluntary donations and supported our fundraising campaigns throughout the year.

I want to thank Jean Phillips-Martinson for her very generous donation for the second year in a row, which has helped provide us with much financial stability.

And a special thanks to my colleagues on the Finance and Fundraising Committee, Craig Moore, and Joan Gardiner, and to Tony Holland and the Trustees for their leadership and to Marguerite Hughes and the IPWSO staff for all their support in 2021.

INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 31 DECEMBER 2021

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 2021.

Responsibilities and Basis of Report

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

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

Independent Examiner's Statement

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

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

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

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

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.

INDEPENDENT EXAMINER'S REPORT (CONTINUED)
FOR THE YEAR ENDED 31 DECEMBER 2021

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: 1 March 2022

M Hewett FCA DChA
Peters Elworthy & Moore

Chartered Accountants

Cambridge

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 DECEMBER 2021

	Note	Restricted funds 2021 £	Unrestricted funds 2021 £	Total funds 2021 £	Total funds 2020 £
Income from:					
Donations	2	**-**	**72,117**	**72,117**	68,660
Charitable activities	3	**166,758**	**7,710**	**174,468**	43,336
Total income		**166,758**	**79,827**	**246,585**	111,996
Expenditure on:					
Charitable activities	4	**113,658**	**48,257**	**161,915**	70,233
Total expenditure		**113,658**	**48,257**	**161,915**	70,233
Net income before net losses on investments		**53,100**	**31,570**	**84,670**	41,763
Net losses on investments		**-**	**(628)**	**(628)**	-
Net income		**53,100**	**30,942**	**84,042**	41,763
Transfers between funds	12	**(3,849)**	**3,849**	**-**	-
Net movement in funds		**49,251**	**34,791**	**84,042**	41,763
Reconciliation of funds:					
Total funds brought forward		**15,136**	**146,194**	**161,330**	119,567
Total funds carried forward		**64,387**	**180,985**	**245,372**	161,330

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

BALANCE SHEET
AS AT 31 DECEMBER 2021

	Note		2021 £		As restated 2020 £
Fixed assets					
Investments	8		-		5,452
			-		5,452
Current assets					
Debtors	9	**17,314**		446	
Cash at bank and in hand		**282,626**		158,619	
		299,940		159,065	
Creditors: amounts falling due within one year	10	**(54,568)**		(3,187)	
Net current assets			**245,372**		155,878
Total assets less current liabilities			**245,372**		161,330
Total net assets			**245,372**		161,330
Charity funds					
Restricted funds	12		**64,387**		15,136
Unrestricted funds	12		**180,985**		146,194
Total funds			**245,372**		161,330

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

Marcello Giannubilo Schutzer

Date: 22/02/2022

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.

The accounts were previously presented on a receipts and payments basis and the balance sheet has been restated following the change to the accruals basis.

The financial statements have been presented in pounds sterling which is the currency that the financial records are maintained in, however the functional currency includes £, $ and €.

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.

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 sterling at rates of exchange ruling at the reporting date.

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

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

1. Accounting policies (continued)

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.

1.8 Debtors

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

1.9 Cash at bank and in hand

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

1.10 Liabilities and provisions

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

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

1.11 Financial instruments

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

1.12 Pensions

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

2. Income from donations

	Unrestricted funds 2021 £	**Total funds 2021 £**	As restated Total funds 2020 £
Donations	72,117	**72,117**	68,660
Total 2020 as restated	68,660	68,660	

Included in donations is £48,676 (2020: £39,062) received in the form of donated investments from Mrs Jean Phillips-Martinsson. This income is unrestricted and more information is available in the Statement of Funds note.

3. Income from charitable activities

	Restricted funds 2021 £	**Unrestricted funds 2021 £**	**Total funds 2021 £**	As restated Total funds 2020 £
Member subscriptions	-	7,710	**7,710**	6,474
Grants	163,025	-	**163,025**	36,862
Donations	3,733	-	**3,733**	-
	166,758	7,710	**174,468**	43,336
Total 2020 as restated	36,862	6,474	43,336	

4. Analysis of expenditure by activities

	Activities undertaken directly 2021 £	**Support costs 2021 £**	**Total funds 2021 £**	As restated Total funds 2020 £
Charitable expenditure	143,887	18,028	**161,915**	70,233
Total 2020 as restated	61,332	8,901	70,233	

Analysis of direct costs

	Total funds 2021 £	Total funds 2020 £
Staff costs	**86,425**	42,073
ECHO project	**13,255**	806
Conferences and events costs	**32,323**	943
Diagnostic testing	**3,522**	2,130
Website costs	**7,178**	14,477
Clinical Trial Consortium	**714**	815
Translations	**470**	88
	143,887	61,332

4. Analysis of expenditure by activities (continued)

Analysis of support costs

	Total funds 2021 £	Total funds 2020 £
Accountancy and bookkeeping fees	**6,397**	5,501
Foreign currency exchange	**5,559**	(235)
Advertising and marketing	**1,566**	490
Insurance	**1,152**	619
IT software and consumables	**839**	291
Bank charges	**824**	235
Miscellaneous expenses	**452**	777
Office running costs	**1,239**	1,223
	18,028	8,901

5. Independent examiner's remuneration

The independent examiner's remuneration amounts to an independent examiner fee of £1,236 *(*2020 - £1,200*)*, accountancy services of £1,764 (2020 - £1,020) and bookkeeping fees of £3,397 (2020 - £3,281).

6. Staff costs and key management personnel

	2021 **£**	2020 £
Wages and salaries	**83,219**	40,598
Social security costs	**1,686**	785
Contribution to defined contribution pension schemes	**1,520**	690
	86,425	42,073

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

	2021 **No.**	2020 No.
Staff	**4**	3

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, employers' national insurance and employers' pension contribution) totalling £15,038 (2020: £11,760).

7. Trustees' remuneration and expenses

During the year, no Trustees received any remuneration or other benefits (2020 - £NIL).

During the year ended 31 December 2021, no Trustee expenses have been incurred (2020 - £NIL) and no expenses have been paid directly to a third party on their behalf.

8. Fixed asset investments

	Listed investments £
Prior year adjustment	**5,452**
At 1 January 2021 (market value)	**5,452**
Additions	**48,676**
Disposals at market value (proceeds £53,500, realised loss £628)	**(54,128)**
At 31 December 2021	**-**

All the fixed asset investments are held in the UK. All investment additions have been donated to the CIO and are recognised at the market value on the date of the donation. The 2020 accounts were prepared on the receipts and payments basis so the investments held at that date have been introduced into these financial statements via a prior year adjustment (see note 11) using the market value on 31 December 2020.

All investments are carried at their fair value. Holdings in common investment funds, unit trusts and open ended investment companies are at the bid price. The basis of fair value for quoted investments is equivalent to the market value, using the bid price. Asset sales and purchases are recognised at the date of trade at cost (that is their transaction value).

The CIO does not make use of derivatives and similar complex financial instruments and at the year end the CIO was not holding any shares.

9. Debtors

	2021 £	As restated 2020 £
Due within one year		
Trade debtors	**17,314**	446
	17,314	446

10. Creditors: Amounts falling due within one year

	2021 **£**	As restated 2020 £
Trade creditors	**58**	81
Other taxation and social security	**727**	485
Other creditors	**302**	173
Accruals and deferred income	**53,481**	2,448
	54,568	3,187

	2021 **£**	2020 £
Resources deferred during the year	**49,002**	-

Deferred income relates to sponsorship income received for the 2022 conference to be held in Ireland. Sponsorship has been received from Resilience Care, Radius Health Inc and Novo Nordisk.

11. Prior year adjustments

A prior year adjustment has been made in order to restate the opening fund position for the CIO because the 2020 accounts were prepared on the receipts and payments basis, however the 2021 accounts are being prepared using the accruals method.

At the end of 2020 there were unrestricted funds carried forward on the receipts and payments accounts of £143,483 and restricted funds of £15,136. After adjusting for investments at market value of £5,452, debtors of £446, and creditors of £3,187, the revised opening balance position at 1 January 2021 was £161,330, of which £15,136 was restricted and £146,194 was unrestricted.

12. Statement of funds

Statement of funds - current year

	Balance at 1 January 2021 £	Income £	Expenditure £	Transfers in/out £	Gains/ (Losses) £	Balance at 31 December 2021 £
Unrestricted funds						
General Funds	**146,194**	**79,827**	**(48,257)**	**3,849**	**(628)**	**180,985**
Restricted funds						
IPWSO Conference/ Meeting Fund	**14,123**	**32,194**	**(9,737)**	**-**	**-**	**36,580**
Diagnostic testing	**1,013**	**7,055**	**(3,858)**	**-**	**-**	**4,210**
ECHO Funding	**-**	**76,494**	**(58,356)**	**(3,849)**	**-**	**14,289**
Raising Awareness	**-**	**3,075**	**(1,334)**	**-**	**-**	**1,741**
IPWSO at 30	**-**	**34,447**	**(34,447)**	**-**	**-**	**-**
Mental Health Workshop	**-**	**7,567**	**-**	**-**	**-**	**7,567**
International Advocacy Support	**-**	**5,427**	**(5,427)**	**-**	**-**	**-**
Education and Learning Support	**-**	**499**	**(499)**	**-**	**-**	**-**
	15,136	**166,758**	**(113,658)**	**(3,849)**	**-**	**64,387**
Total of funds	**161,330**	**246,585**	**(161,915)**	**-**	**(628)**	**245,372**

12. Statement of funds (continued)

Statement of funds - prior year

	Balance at 1 January 2020 £	As restated Income £	As restated Expenditure £	Balance at 31 December 2020 £
Unrestricted funds				
General Funds	117,932	71,991	(43,729)	146,194
Restricted funds				
IPWSO Conference/ Meeting Fund	1,635	12,488	-	14,123
Website Fund	-	24,374	(24,374)	-
Diagnostic testing	-	3,143	(2,130)	1,013
	1,635	40,005	(26,504)	15,136
Total of funds	119,567	111,996	(70,233)	161,330

12. 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, including travel scholarships for parents and professionals.

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. Four ECHO projects took place in 2021 – the Leadership, Health, Latino-America and Caregivers. Funds were received from Pfizer and Friends of IPWSO USA in 2021.

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. £23,314 of the grant funding has therefore been disclosed as sponsorship income, which is deferred to 2022 (see note 9).

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

Website Fund - Money received in 2020 from Friends of IPWSO USA specifically used to create and develop the website.

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

Education and Learning Support - A donation was received from Johnson & Johnson to be used for education and resources in support of learning (intellectual disabilities).

Superheroes Project – Funds from the University Court of the University of Edinburgh to support a venture with the University of Glasgow which brings together artists, researchers, people living with PWS and their families and carers to create an art exhibition about the challenges and experiences of living with PWS.

A transfer between funds may arise where costs have been incurred in an earlier year, prior to a restricted fund project being established.

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

13. Analysis of net assets between funds

Analysis of net assets between funds - current year

	Restricted funds 2021 £	**Unrestricted funds 2021 £**	**Total funds 2021 £**
Current assets	64,387	235,553	**299,940**
Creditors due within one year	-	(54,568)	**(54,568)**
Total	64,387	180,985	**245,372**

Analysis of net assets between funds - prior year

	Restricted funds 2020 £	Unrestricted funds 2020 £	Total funds 2020 £
Fixed asset investments	-	5,452	5,452
Current assets	15,136	143,929	159,065
Creditors due within one year	-	(3,187)	(3,187)
Total	15,136	146,194	161,330

14. Pension commitments

The CIO operates a defined contribution pension scheme. The assets of the scheme are held separately from those of the group in an independently administered fund. The pension cost charge represents contributions payable by the group to the fund and amounted to £1,520 (2020 - £517). £173 (2020 - £68) were payable to the fund at the balance sheet date and are included in creditors.

15. Related party transactions

The CIO has not entered into any related party transaction during the current or previous year, nor are there any outstanding balances owing between related parties and the CIO at 31 December 2021.

Advisory boards

Clinical and Scientific Advisory Board: Dan Driscoll

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, psychiatry, gastroenterology, and orthopaedic surgery.

Scientific papers:

The CSAB has continued to prepare documents 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 should go 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 developed a standardised form for queries. During this past year members of the CSAB have responded to requests for advice on a number of topics.

The CSAB has put together a one page, easy to read document of important medical facts about PWS for families to use when seeing busy clinicians and emergency personnel. This is now on the website and can be translated into multiple languages.

IPWSO international conference in Ireland, July 2022:

The CSAB has been meeting monthly by Zoom to discuss plans for the International Clinical and Scientific meeting in Ireland in 2022. Mental health will be a primary focus with four international scientists giving invited presentations. There will also be talks and poster sessions on a wide variety of topics about PWS.

Other matters:

Numerous research clinical trials involving PWS are currently being conducted in different parts of the world. The CSAB is keeping abreast of these trials and will report on promising results as they become available.

Famcare Board: Verena Gutmann

We are a team of seven women from six different countries, experts as well as mothers, with a long experience accompanying individuals with PWS. We meet every second month by Zoom to discuss topics which we consider relevant and of interest to communicate to you, our international IPWSO family.

This year we worked on three different topics:

- The Importance of Planned, Purposeful Days
- Too hot - too cold: Temperature sensation
- Selecting a school environment for my child with PWS

The first article you can find already on our website, and it was also a topic of one of the Zoom conferences held this year.

The other two topics will soon be uploaded to the website and also publicised in our newsletters and on our social media. We know it is important to publish and discuss our articles widely on different media with the purpose of reaching as many families as possible.

If you have questions or topics, you consider important in your family life, please contact us via the IPWSO office on office@ipwso.org.

Wishing you all an easier year in 2022, and strength in managing the challenges of PWS.

Professional Providers and Caregivers Board: Lynn Garrick

Despite the planning and anticipation of the caregiver's conference in Berlin (August 2021), the decision was made to cancel for the safety of all the participants. The cancellation of the conference was disappointing but furthered the resolve to bring knowledge and training to caregivers worldwide.

The Professional Providers and Caregivers Board (PPCB) remains steadfast in expanding the knowledge and approaches supporting those living with Prader -Willi syndrome (PWS). It remains essential to examine how we support individuals living with PWS in this ever-changing and increasingly technological and connected world. For some regions of the world, services for PWS are in their infancy, while others have been providing support for decades. There is something to be learned and applied in every circumstance. We are indeed a global family of caregivers.

The PPCB has been working diligently to develop a robust program for the 2022 conference in Ireland. In 2021, the PPCB participated in Project ECHO, which allows people from all over the world to share expertise, learn from each other and challenge ourselves to think from new perspectives. Speakers from around the globe give everyone the opportunity to learn how different areas approach support for those with PWS, learn from each other, and challenge the old ways of thinking to allow for the most inclusive, meaningful, self- determined lives for people living with PWS.

On a personal note, it is my honour to follow in the footsteps of Norbert Hödebeck-Stuntebeck, who will remain on the PPCB. Norbert continues to work tirelessly to ensure that caregivers worldwide have access to the most up-to-date information and training relating to caregiving for people with PWS. He has helped countless people through his tireless search for knowledge and ability to see the possibilities in every individual.

I have the pleasure of working alongside genuinely passionate, caring, and knowledgeable individuals committed to the same vision. My heartfelt thanks to the current PPCB members: Laura Keane, Norbert Hödebeck-Stuntebeck, Damien Jones, Hubert Soyer, Patrice Carroll, Larry Genstil, Neil Gumley, Mary Ziccardi, and Jackie Mallow.

Projects

Conferences and workshops: Lynn Garrick

The Conferences and Workshops Committee remained active in 2021 despite the ongoing limitations of in-person conferences. While we miss the opportunity to be in person, having virtual conferences has provided new opportunities to reach a broader audience. 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 2022. With the ongoing support of Friends of IPWSO (USA), we are able to help countries provide education and training on Prader-Willi syndrome.

Asia-Pacific region

The Asia Pacific Conference was a three-day virtual event held in October 2021. Each day there were different topics. Day one was focused on science, day two on care and support and day three was a *Hear Our Voices* session where parents, other family members and people with PWS were able to present their stories. IPWSO was involved in this major conference as the global principal organisation and provided financial support to enable up to 70 family members from Vietnam, Indonesia, India, China and Malaysia to attend. Many members of our board and various committees provided presentations during this conference.

Colombia

The Asociación Colombiana Síndrome de Prader-Willi organised a three-day virtual conference in July 2021. This conference featured clinical and scientific speakers as well as speakers on topics geared towards families and caregivers. Many members of our Board and various committees were presenters at this conference.

India

The Board of Genetic Counselling, India held a workshop in July 2021 with 1,450 participants. One of the three days of this conference was dedicated to Prader-Willi syndrome. Topics included genetics, diagnosis, overview of the lifespan of those with Prader-Willi syndrome and specific care needs. IPWSO provided funding towards the workshop and Professor Tony Holland provided a presentation.

In September IPWSO provided support and advice to facilitate the hosting of an Indian Prader-Willi Syndrome Association (IPWSA) online workshop on Growth Hormone treatment in PWS.

The 11th International Prader-Willi Syndrome Organisation Conference, University of Limerick campus, Ireland, 6 – 10 July 2022: Nora McNairney

One of the focal points of IPWSO’s work is our International Conference, a unique and immersive event that brings together the global PWS community with the aim of sharing knowledge and enabling a better understanding of the needs of people with PWS. The Planning Committee and Programme Leads met regularly in 2021 to discuss the format, identify speakers and topics. Set against the ever-changing background of the COVID pandemic, their other major consideration was to monitor and evaluate the challenges of an in-person event in these unprecedented circumstances.

The programmes for each of the six strands of the Conference are now well developed and further details are available on our website; details of travel grant opportunities, generously funded by Friends of IPWSO (USA), have been circulated, as have the call for abstracts for oral and poster presentations for the Clinical and Scientific Conference and the Professional Providers and Caregivers Conference; registration at the early bird rate is open and will remain so until 7 April 2022.

Marguerite Hughes, CEO of IPWSO, accompanied by Gary Brennan, National Development Manager, Prader-Willi Syndrome Association of Ireland, and Nora McNairney, Project Manager at IPWSO, carried out a second site visit in September 2021 and Marguerite had the pleasure of signing the contract with the University of Limerick – an excellent venue boasting superb conference and accommodation facilities.

The Programme Leads and Committees have worked very hard to identify a wide range of topics that will be of interest to IPWSO’s global multidisciplinary audience as well as to people living with PWS, their families, carers and all those providing a holistic approach to supporting the health, education and social care requirements of people living with the syndrome. Expert speakers have been secured who can deliver the most current thinking and facilitate what will no doubt lead to interesting debates and discussions.

IPWSO is indebted to our Platinum Sponsors, Novo Nordisk A/S and Radius Health, and to Friends of IPWSO USA, and the Foundation for Prader-Willi Research. Thanks also to our Gold Sponsors, Saniona, Resilience, and PWSA | USA, and our Bronze Sponsors, OT4B and the PWS Associations in Switzerland and Belgium. Fáilte Ireland and the Hospital Saturday Fund have also provided financial assistance for IPWSO 2022.

The support of these organisations significantly reduces the cost of registration fees and permits access to delegates who may not otherwise have the resources to attend.

If you are interested in sponsorship opportunities, do visit the website for more details and get in touch.

We are also grateful to our Planning Committee Leads and members of each of the Committees for their work in compiling the programmes and their guidance and support. A special word of thanks to Norbert Höedebeck-Stuntebeck, whose term in office as Lead for the Professional Providers and Caregivers Conference ended in 2021. Norbert is replaced by Laura Keane.

Spreading the word about our Conference across the globe to clinicians, researchers, academics, parents, families, people living with PWS, professional providers and caregivers, educationalists and allied health professionals, is key to its success; if you would like to show your support see our marketing toolkit for some helpful resources and ideas.

The countdown is now on! Register now and we look forward to meeting you in Limerick very soon.

Project ECHO®: James O’Brien

Project ECHO® (Extension of Community Healthcare Outcomes) is the name of our innovative online PWS telementoring community. We designed the project specifically for people who wish to grow and develop PWS associations and build knowledge and understanding of the syndrome in their countries. Following a successful pilot of the IPWSO Leadership ECHO® in 2020, we have been privileged to expand the offering to three additional PWS audiences.

The IPWSO Health ECHO® began in February 2021 with the objective of assisting health professionals who work with people with PWS to deepen their understanding of the syndrome.

Like the Health ECHO, the IPWSO SPW Latino América ECHO® is oriented towards health and allied professionals. This programme began in March 2021 and was an intensive weekly programme over 3.5 months, delivered in Spanish and managed by RedLASPW, the Latin American Network of Prader-Willi Syndrome.

The IPWSO Caregivers’ ECHO®, aimed at Caregivers and Providers who are in contact with people with PWS in an all-day setting, began in May 2021.

The Leadership ECHO, for people who are active in existing associations and others who are starting on the journey to establish groups or associations within their country, also continued going strong in 2021.

In total, an incredible 388 participants from 51 countries joined at least one of our 46 IPWSO ECHO sessions in 2021.

A key driver for the IPWSO ECHO programme is that we have ongoing resources which are available to the whole PWS community. The didactics presented by expert speakers at each session are recorded and made accessible to anyone via the IPWSO website and YouTube. Almost 30 hours of video content on numerous topics and disciplines involved in supporting this complex rare disease is now available alongside documents relevant to each topic.

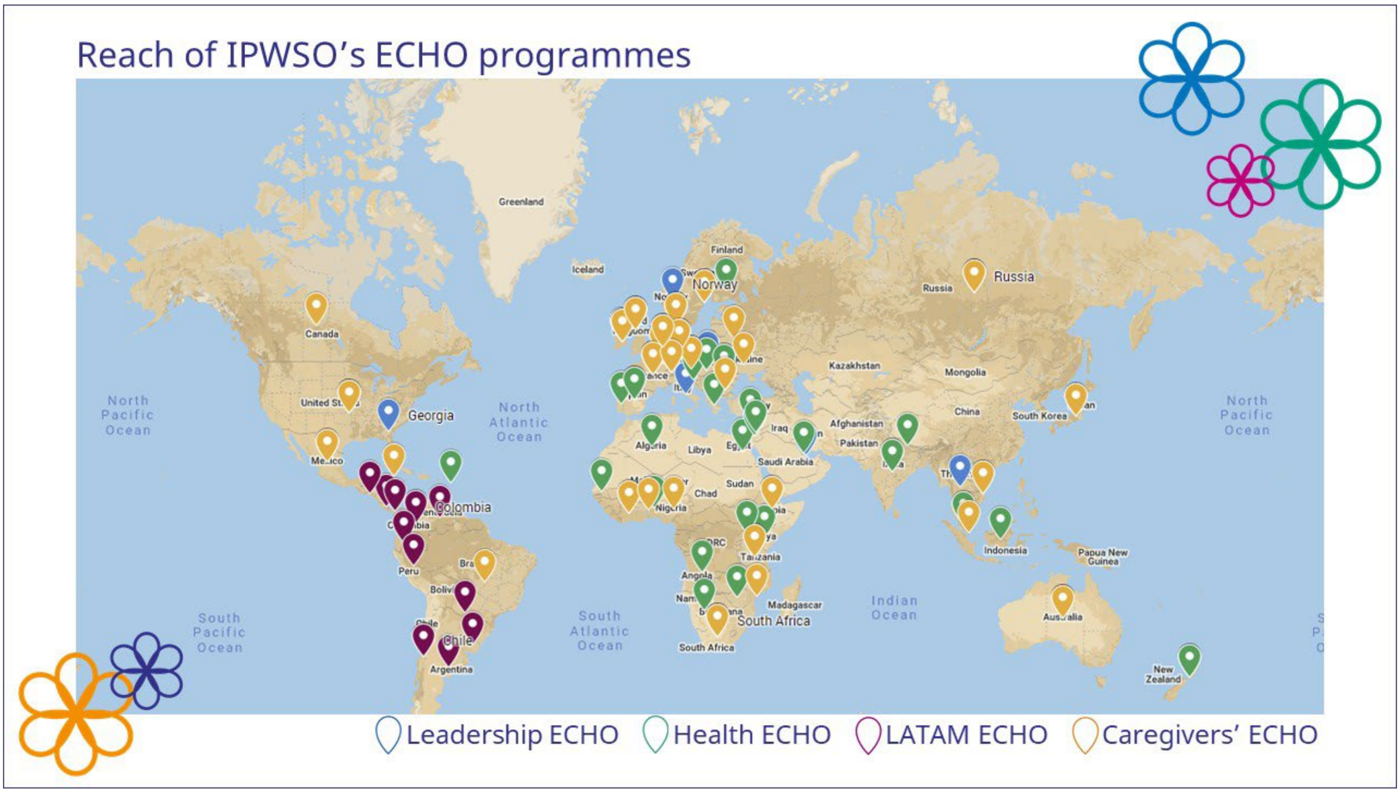
Our ECHO feedback and surveys demonstrate that the sessions are successful in improving the abilities and knowledge of the participants. According to survey data, participants now understand more about PWS; how people with PWS feel and think; current healthcare recommendations and best practice for people with PWS; and current social care and best practice recommendations for people with PWS. We also have evidence that the knowledge learnt during the sessions is further shared within regional communities and several participants are keen to establish PWS ECHOs within their countries.

We are indebted to Pfizer Inc. for their financial support of the Leadership, Health, and SPW Latino América ECHOs, and to Friends of IPWSO (USA) for their financial support of the Caregivers’ ECHO. None of these programmes would have been possible without their generosity.

We are grateful to all those subject experts who gave presentations over the course of the year. Very many thanks to Tony Holland, Georgina Loughnan, Amalia Balart and the team at RedLASPW, Norbert Höedebeck-Stuntebeck, Hubert Soyer and Patrice Carroll, who are core to the success of the ECHO project and volunteer a great number of hours.

We also extend our thanks to the University of New Mexico and the ECHO® Project for providing us with the framework and Zoom technology that makes this initiative possible.

Finally, very many thanks to our participants for sharing your experience, stories, and expertise – we’ve been honoured to provide a platform which brings our PWS community together online.


Reach of IPWSO’s ECHO programmes

Policy and research: Maria Libura

IPWSO is in a unique position having contacts in many countries across the world and, although IPWSO prime role is not research, we recognise that there are some issues that can be best addressed through research at a global level.

COVID-19 study

This past year we completed a survey of how COVID-19 infections presented in people with PWS and the outcomes. Thank you to family members and professional care providers who completed our online forms when someone with PWS they supported developed COVID. Contrary to our expectations we found that people with PWS tended to have very mild disease, to present in a similar way to others, and to make a good recovery. Although tragically we have heard of deaths, those that have died would appear to have had many other health problems. This observation of a mild disease and good outcomes has also been supported by research from France. Our paper reporting the findings has now been published in the Orphanet Journal of Rare Diseases. Thank you particularly to Agnes Hoctor and Joyce Whittington for all their work supporting this.

Choice and control: the use of restrictive practices in the care of people with Prader-Willi syndrome

Elisabeth Fistein at the University of Cambridge, UK, and her colleagues reported findings from a systematic review of Court judgements in English speaking jurisdictions, where the Court had been asked to determine how someone with PWS should be supported. This is part of a wider study of the use of restrictive practices in the support of people with PWS. This has also included a systematic review by Sarah Bellis and colleagues of the research literature on illness and causes of death in people with PWS. The idea is to use findings and examples from across the world to illustrate the serious outcomes where access to food is uncontrolled, and to try and develop good practice in the support of people with PWS, establishing what is acceptable and what is not acceptable in terms of restrictions particularly with respect to the support of adults with PWS. IPWSO is committed to the principles set out in the UN Convention on the Rights of Persons with Disabilities but this does raise tensions when someone with PWS is eating too much and their life is at risk due to extreme obesity, or their behaviour is very problematic.

Supporting Adults with PWS in the Community Research

In late 2019 IPWSO assembled a team of researchers to investigate whether data that had already been collected by service providers could be used to assess whether PWS-specific residential services bring benefit to people with PWS.

Led by Brian Hughes, this study involved identifying what data was already being collected by residential service providers, and then designing and circulating an instrument to collect relevant data.

By the end of 2021, 10 organisations from 6 countries had submitted data with additional data expected in early 2022. The Research Team is very grateful to the organisations that are participating in this study and looks forward to analysing and reporting on the research in 2022.

Mental Health Network

The mental wellbeing of people with Prader-Willi syndrome (PWS) is a major concern for them, their families and other care providers, and the presence of mental-ill health and/or behaviour problems is often cited as the single most significant impediment to a more independent and fulfilling life for people with PWS.

The rarity of PWS means that there are few psychiatrists, psychologists or other mental health professionals who support a large number of people with Prader-Willi syndrome. The absence of a network to connect mental health professionals who support people with PWS and the fact that most mental health professionals support only a small number of people with PWS have inhibited research efforts.

The IPWSO Mental Health Network aims to connect 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. Ultimately it is hoped that research undertaken as part of the IPWSO Mental Health Network will result in best practice guidelines that aim to optimise wellbeing and best enable the prevention, detection, and treatment of mental ill-health and problem behaviours for people with PWS.

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

International advocacy: Marguerite Hughes

IPWSO Affiliations

In 2021 IPWSO was a member of or formally affiliated with the following international organisations:

- BOND – The International Development Network
- 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 2021:

1. **Campaign for a UN Resolution on Persons Living with a Rare Disease**
   Throughout 2021 IPWSO updated its members and supporters by social media, in its newsletters, and in individual correspondence on the campaign for a UN resolution, which was led by RDI, the NGO Committee for Rare Diseases and EURORDIS. The Resolution was adopted by the UN General Assembly on 16 December 2021.

2. **Advocacy Mentorship**
   In March 2021 IPWSO invited Flaminia Macchia, Executive Director and Hlawulani Mkhabela, Outreach and Engagement Manager, Rare Diseases International to present at its Leadership ECHO programme on International Advocacy and Global Collaboration for rare diseases. This session was attended by leaders from PWS associations worldwide and is available to watch via IPWSO's website. This session sought to both update PWS association leaders on current advocacy initiatives and to prepare them for future advocacy efforts.

3. **Collaborative Global Network for Rare Diseases (CGN4RD)**
   The WHO and RDI are exploring a model 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 Tony Holland, IPWSO President, are members of the advisory panel of experts and they participated in a series of workshops throughout 2021 designed to advance both the concept and methodological model for the CGN4RD.

4. **Universal Health Coverage**
   In 2021 IPWSO continued to raise awareness of the ongoing campaign led by RDI and EURORDIS to enable patient organisations and the public to call for Universal Health Coverage (UHC) policies and programmes that include rare diseases.

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

1. **Global Genes**
   IPWSO involvement in Global Genes is led by our Vice-President, James O'Brien. James is a member of the Global Genes RARE Advocacy Leadership Council, which is made up of patient advocates from around the world. During 2021 James worked with others to organise and host the 1st Global Genes International Regional Meeting for Australasia. Designed to stimulate greater regional participation in Global Genes ongoing international advocacy, this forum formed part of Global Genes RARE Patient Advocacy Summit.

   James also presented to the Global Genes RARE Foundation Alliance sharing knowledge and research in relation to IPWSO's ECHO projects.

2. **Rare Disease Ghana Initiative (RDGI)**
   In October Marguerite Hughes and Tony Holland presented a webinar on Diagnosis and Management of Prader-Willi syndrome to an audience of medical and allied professionals in Ghana.

   IPWSO is also working with RDGI on supporting free diagnostic testing for people with PWS in Ghana.

3. **IAPO's 3rd Asia Pacific Patients Congress**
   In November James O'Brien presented at the 3rd Asia Pacific Patients Congress on IPWSO's ECHO programmes as an example of how to strengthen health systems through patient co-creation and re-orientation of healthcare using digital healthcare.

In 2021 IPWSO also continued to raise awareness through presentations, advertising and the hosting of information booths at relevant medical conferences including the European Congress of Endocrinology (ECE), the European Society of Paediatric and Adolescent Endocrinology (ESPE), and the African Society for Paediatric and Adolescent Endocrinology (ASPAE).

Sincere thanks to Saniona for supporting this important project. International advocacy on behalf of the global PWS community has long been identified as a priority by IPWSO's member associations, including at its recent 30th Anniversary workshop.

Diagnostic testing: Marguerite Hughes

For the 19th consecutive year IPWSO offered free diagnostic testing for PWS to families unable to access testing in their own countries. This service was provided in collaboration with the Baschirotto Institute for Rare Diseases (BIRD), which is based in Vicenza, Italy. All tests conducted on behalf of IPWSO in 2021 were paid for through generous sponsorship received from OT4B.

Since the inception of its free diagnostic testing service, IPWSO has funded testing for over 500 families around the world. As far as we are aware, IPWSO is the only organisation that provides this service for PWS or any other rare disease.

The success of IPWSO's diagnostic testing programme relies on doctors and families who would benefit from this service knowing that it exists and how to access it.

Throughout 2021 IPWSO used its social media to raise awareness of the service, as well as promoting it through relevant conferences, meetings, and in individual correspondence with families and professionals worldwide.

In 2021 IPWSO funded the testing of 19 samples, which were sent from Georgia, Guatemala and Peru. The ages of those diagnosed with PWS ranged from less than 1 year to 16 years.

In late 2021, IPWSO, with support from Friends of IPWSO (USA), provided funding to the Brazilian PWS association, Associação Brasileira da Síndrome de Prader-Willi, to promote awareness of a new free diagnostic testing service for PWS that is being offered by the Instituto Fernandes Figueira in Rio de Janeiro. It is hoped that this will allow many additional families in Brazil to secure diagnoses for their children.

We encourage all IPWSO supporters to continue to share information about this service.

Website and Publications: François Besnier

The work of the Website and Publications Committee has continued from the sound basis of projects initiated in 2020.

Website and social media

The website, which was launched at the end of 2020 has become a fantastic resource and tool in support of our work. Minor improvements were made this year to improve its useability including the addition of a search tool, minor bug corrections and changes on some page designs. We have seen a very positive increase in visitors to the site up 173% on 2020 figures, and page views up 144%.

New items have been added to reflect and highlight our new activities and work: in particular the development of the ECHO resources which now include numerous films, presentations and useful papers; a new section to support the programme and registration for IPWSO 2022 conference; and the continued development of the information sections as more factsheets and translations are published across the organisation. The blog section is now a living part of the site, allowing a variety of different views and situations to be presented.

We have seen a positive response to the use of Google Translate on the site. We are aware that it functions better in some languages than others, but we are optimistic that it continues to improve in quality. We still direct website visitors to our professionally translated papers in the first instance. The ability to communicate our information in a way that can be accessible to people around the world is an on-going challenge for any international organisation, and this will remain an important part of our future work: identifying priority topics and associated languages to reach the people most in need of our help.

Besides the website, other channels have been developed to improve the communication of our information, reaching new audiences, in new ways. We now have a presence on Facebook, Instagram, Twitter, Linkedin and Youtube. We continue to monitor and enjoy developments on Tiktok!

Our monthly newsletter continues to be a key tool for us and is delivered to a growing mailing list. All these actions are reflected by the growing audience for our website as mentioned above.

Publications

An important ongoing piece of work has been in progress to convert our publications into a new format, in line with our new logo and style. The priority has been to promote the new guides for doctors, these are the *Consensus Documents*, developed by our Clinical and Scientific Advisory Board. They have recently been supplemented by a short medical facts guide which we hope will be of use to professionals in a range of settings.

Famcare have also been busy with new work, in particular a guide on *The importance of planned, purposeful days.* We also have a new leaflet which gives a basic introduction to our work as well as an introduction to PWS. This is available in English, Arabic, Spanish and French. Thanks to Friends of IPWSO (USA) for their support with the leaflet.

The challenge for the Website and Publications Committee in 2022 is to offer information in different languages, cultural situations, to different age groups and professional backgrounds to benefit the lives of people with PWS and their families. We also want to give a voice to people with PWS from all over the world.

Advice service: Agnes Hoctor

In addition to the wealth of information and resources on our website, we are also contacted on a regular basis by families and professionals who are looking for particular advice or more in-depth knowledge about an aspect of the care or treatment of a person with PWS.

We often hear from new parents, or grandparents, desperate for information to support a newly diagnosed baby. However, many requests relate to older children or teenagers who may be facing challenges with their weight and diet. Behavioural issues are also a common theme as well as questions about the transition from childhood to adulthood and the options available for adult care in the community.

Growth Hormone Treatment (GHT) is another common theme. Both in terms of access and cost as well as the correct dosage and application. We know that many families simply don't have access to GHT and often feel a huge sense of frustration that they cannot provide their child with this key intervention. Our message is that there are many ways to support your child or adult with PWS and though the benefits of GHT are important, there are many other things you can do. Having a good understanding of the importance of diet and exercise, understanding the behavioural challenges and being equipped with key knowledge will make a significant difference.

In 2021 we heard from people around the world, in over 55 different and disparate countries, including Mongolia, Vietnam, Turkey, Lebanon, Cuba and the Dominican Republic. We received over 170 requests for advice and information via our website, email and social media platforms.

For in-depth advice where the medical background needs to be taken into account, we have an advice form on our website. Requests are responded to by members of our Clinical and Scientific Advisory Board. This is a fantastic resource to be able to provide and we are truly grateful to our CSAB experts who take the time to respond with so much care and attention. A special thank you to Dan Driscoll and Susanne Blichfeldt for their considerable help in 2021.

About us

Who we are

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Amalia Balart
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Laura Keane
Emma Walsh-Tierney (PWSAI)
Kate Woodcock
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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.

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- Attend our next conference in Ireland, 6-10 July 2022

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