

DRAFT Minutes of the IPWSO General Assembly

5pm Irish Standard Time on Sunday 10th July 2022, the University of Limerick, Ireland

1. Welcome

Tony Holland opened the meeting and welcomed delegates and observers in the hall and on Zoom.

2. Apologies

Scott Arant, USA, Maria Libura, Poland.

3. Attendance

40 member countries were eligible to vote (paid members in 2022). Of these 30 either had their delegate present or had nominated a proxy. The meeting was therefore quorate.

In the hall:

2019-2022 Board: Tony Holland (President), UK, Amalia Balart (Trustee), Chile, François Besnier (Trustee), France, Marilyn Dumont-Driscoll (Trustee), USA, Lynn Garrick (Secretary), USA, Verena Gutmann (Trustee), Austria, Craig Moore (Trustee), Australia, James O'Brien (Vice-President), Australia, Kate Woodcock, (Trustee), UK.

Zurab Abjandadze, Georgia, Deborah Barks, Switzerland, Karin Clarke, South Africa, Shelly Cordner (Staff), UK, Leopold Curfs, Netherlands, Jan De Wit, Belgium, Dan Driscoll, USA, Gaby Erazo, Ecuador, Annelies Evens, Belgium, Estela Garcia, Spain, Agnes Hctor (Staff), UK, Marguerite Hughes (CEO), Ireland, Jim Gardner, USA, Joan Gardner, USA, Norbert Hödebeck-Stuntebeck, Germany, Svetlana Labun, Germany, Tünde Liplin, Hungary, Constanze Laemmer, Germany, Juana Muñoz Licerias, Canada, Georgina Loughnan, Australia, Nora McNairney (Staff), UK, Berit Otterlei, Norway, Hubert Platzer, Austria, Johana Quinn, Colombia, Sabina Rebilo, Belgium, Paige Rivard, USA, Marie Solin, Sweden, Hubert Soyer, Germany, Angelika Tomecki, Germany, Michelle Torbert, USA, Li-Ping Tsai, Taiwan, Nicky Van Renterghem, Belgium, Elisa Wanker, Austria.

By Zoom:

2019-2022 Board: Marcello Schutzer (Treasurer), USA.

Nathalie Kayadjanian, USA, Kazue Kurita, Japan, Gloria Queipo, Mexico, Azhar Talib, Malaysia, Lantz Yap, Malaysia.

4. Minutes of the last meeting held on 17th November 2019 in Cojimar, Cuba.

Accepted.

5. Matters arising from the minutes

None.

6. President's report

Tony Holland reported that IPWSO now has 44 members, the newest association to join being SPW Bolivia. We are also delighted that PWS China joined earlier this year and are very active in raising awareness of PWS amongst their families and professionals.

Prof Holland reported on the following projects which are based on our Strategic Plan 2019-22:

- Project ECHO: We have run 4 programmes covering Leadership, Health, Caregivers and a Latin-American specific ECHO. The model has worked well and evaluation has been good, the committee will recommend next steps for this project.
- Free diagnosis: We continue to provide free diagnosis for countries where this is not available and are grateful to our partners who have supported this project over the past three years.
- Conferences and meetings: Covid has had an impact, but we have been pleased to have supported online conferences in Colombia and India as well as the Asia-Pacific PWS conference. More meetings are coming up thanks to funding from Friends of IPWSO (USA). We also held a meeting to celebrate and reflect on our 30th anniversary in 2021 and a Summit meeting on newborn screening.
- Publications: Famcare and the Clinical and Scientific Advisory Board (CSAB) have continued to develop useful publications to support families and professionals. Of particular note is the CSAB's one-page guide to *Important medical facts about Prader-Willi syndrome*.
- Advice line: The advice line continues to be busy with enquiries. There is clearly still a huge disparity in access to diagnosis, care and support around the world, which is reflected in the questions we are asked. We are proud to be able to respond to the individuals involved and grateful to our experts for their input into drafting advice and guidance.
- Advocacy: IPWSO is a member of a number of umbrella bodies that seek to lobby for the rights of people living with rare diseases internationally. We play an active role in several of these groups including Global Genes and RDI to

- amplify the particular needs of people with PWS and their families. We have also been working to develop our contacts and awareness specifically in Africa.
- Individual support to attend meetings and conferences: We have worked with Friends of IPWSO (USA) to secure funding to bring ten delegates to this conference, delegates who would have been unable to attend without this financial support. They were selected following an application process and will take their learnings back to support their work and local connections.
 - Research: We have been involved in a number of pieces of work. This includes a large project around mental health, a draft report was presented earlier in the week. We are also researching the specialist services available to support people with PWS, we conducted research into the impact of the Covid pandemic on the health of people with PWS and had a peer-reviewed paper published. Our advisers have also been involved in the publication of recent papers on growth hormone, hypogonadism, hyperphagia and case law.
 - Organisational resilience: Since the last conference we have completely redeveloped our website and launched a new logo and brand identity. This progress has enabled us to reach new audiences and to take advantage of online communications to achieve our goals. We have also strengthened our capabilities through the adoption of new accounting procedures and software and the move to a CRM. We are registered as a charity in England and Wales and our policies, procedures and financial reporting methods have been developed in line with the law and guidance in the UK.

Prof Holland gave thanks to the huge contribution of our Board members, advisers, staff and volunteers who have carried out this work, as well as the funders who have supported us.

7. Treasurer's report and presentation of the accounts

Marcello Schutzer reported that the Annual Report and Financial Statements of the Charitable Incorporated Organisation (CIO) of IPWSO are prepared in compliance with statutory and constitutional requirements (being on an Accruals rather than Receipts and Payments basis).

Over the last two years, we implemented several changes to better report and manage our accounts:

- Segregated budget between Unrestricted and Restricted (specific purpose imposed by donors).
- Created monthly forecast of income and expenses, allowing forward looking visibility of cash availability for each project.

- Established a Virtual Finance Office to maintain IPWSO accounting records on a monthly basis.
- Replaced Excel spreadsheets with Xero software.
- Elected USD as the functional currency for monthly management reports.

Mr Schutzer noted that we have consistently maintained cash reserves above the minimum level of USD 125k. A summary of the accounts was presented which is shown below.

IPWSO FINANCIAL STATEMENTS (2020-2021)

Values in GBP	2020	2021		
	Total	Unrestricted	Restricted	Total
Donations	68,660	72,117	-	72,117
Member subscriptions	6,474	7,710	-	7,710
Grants	36,862	-	163,025	163,025
Others	-	-	3,733	3,733
Total Income (A)	111,996	79,827	166,758	246,585
Total Expenditures (B)	70,233	48,257	113,658	161,915
Operational Net Income (A) - (B)	41,763	31,570	53,100	84,670
Net losses on investments		(628)	-	(628)
Transfers between funds		3,849	(3,849)	-
Net Funds Movement (C)	41,763	34,791	49,251	84,042
Beginning Balance (D)	119,567	146,194	15,136	161,330
Year End Balance (C) + (D)	161,330	180,985	64,387	245,372

Restricted Funds as of December 31st, 2021

IPWSO Conference	36,580
ECHO Funding	14,289
Mental Health Workshop	7,567
Diagnostic Testing	4,210
Raising Awareness	1,741
Total	64,387

IPWSO EXPENDITURES (2020-2021)

Expenditures (values in GBP)	2020		2021	
Staff Costs	42,073	59.9%	86,425	53.4%
Conferences and Events Costs	943	1.3%	32,323	20.0%
ECHO Project	806	1.1%	13,255	8.2%
Website Costs	14,477	20.6%	7,178	4.4%
Accountancy bookkeeping Fees	5,501	7.8%	6,397	4.0%
Foreign Currency Exchange	(235)	-0.3%	5,559	3.4%
Diagnostic Testing	2,130	3.0%	3,522	2.2%
Advertising & Marketing	490	0.7%	1,566	1.0%
Office Costs	1,223	1.7%	1,239	0.8%
Insurance	619	0.9%	1,152	0.7%
All others	2,206	3.1%	3,299	2.0%
Total	70,233	100.0%	161,915	100.0%

8. Election of the Trustees

James O'Brien took the chair and invited the nominees to present themselves.

The nominee for President was: Tony Holland, UK.

The nominees for Trustees were: Scott Arant, USA, (his statement was read by the chair in his absence) François Besnier, France, Gaby Erazo, Ecuador, Lynn Garrick, USA, Svetlana Labun, Germany, Tünde Liplin, Hungary, Craig Moore, Australia, Kate Woodcock, UK and Lantz Yap, Malaysia.

There were no objections to the slate of candidates proposed and they were duly elected to the Board for the term of 2022-25.

The new Board recommended the appointment of the following candidates as co-opted Trustees: Karin Clarke, South Africa and Nathalie Kayadjanian, USA and they were also asked to present themselves to the meeting.

9. Presentations and thanks

a. Outgoing Trustees

Amalia Balart, Marilyn Dumont-Driscoll, Verena Gutmann, Maria Libura, James O'Brien and Marcello Schutzer were all thanked for their huge contributions to the work of IPWSO.

b. Norbert Hödebeck-Stuntebeck

The meeting gave particular thanks to Norbert Hödebeck-Stuntebeck for all his service to IPWSO's Professional Providers and Caregivers Board.

c. Boards, Committees and Advisers

The meeting gave thanks to Jean Phillips-Martinsson in her role as Honorary President, the chairs of the advisory boards, Dan Driscoll, Lynn Garrick and Verena Gutmann and the many advisers, volunteers and donors who support the work of IPWSO.

d. Conference team

The conference planning committee was thanked for developing an excellent programme for the event. Nora McNairney was thanked for her tremendous work in organising the conference. The staff, Board and Advisers of IPWSO were also thanked for their roles in the running of the event. Thanks were also extended to the venue and hotel staff and the suppliers.

10. IPWSO conference 2025

a. Resolution to extend deadline for bids

The Board of IPWSO proposed a resolution to delay the decision about the venue for the 2025 conference to a later date of 31 January 2023. This was due to the uncertainty caused by recent global events which had meant that no bid had been received. The members were asked to vote and the resolution was passed unanimously.

11. Any other business

None received, the meeting ended at 6pm Irish Standard Time.