



**DRAFT Minutes of the IPWSO General Assembly held at 5pm on Sunday 17th
November 2019 at the Theatre, Cojimar Conference Centre, Havana, Cuba**

1. Welcome

Tony Holland opened the meeting by welcoming the delegates to the General Assembly, IPWSO's administrative meeting that traditionally closes the international conference. He thanked the Cuban organisers and IPWSO team who had organised the week's events.

2. Apologies

François Besnier, France and Marcello Schutzer, USA.

3. Attendance

Marilyn Dumont-Driscoll, IPWSO Secretary, noted that IPWSO had 34 paid up members who were entitled to vote. She confirmed that a quorum existed as 33 of these were represented at the meeting (either in person or by proxy).

1. IPWSO President, Tony Holland, UK
2. IPWSO Vice-President, Marguerite Hughes, Ireland
3. IPWSO Treasurer, Hubert Soyer, Germany
4. IPWSO Secretary, Marilyn Dumont-Driscoll, USA
5. IPWSO Board Member, Mariona Nadal, Spain
6. IPWSO Board Member, Amalia Balart, Chile
7. IPWSO Board Member, Verena Gutmann, Austria
8. IPWSO Board Member, June-Anne Gold, UK
9. IPWSO Board Member, James O'Brien, Australia
10. IPWSO Board Member & Chair of Famcare, Georgina Loughnan, Australia
11. IPWSO CSAB Chair, Dan Driscoll, USA
12. IPWSO PPCB Chair, Norbert Hödebeck-Stuntebeck, Germany
13. Jan de Wit, Belgium
14. Sandra de Keyzer, Netherlands
15. Carolina Cardenas Vargas, Colombia
16. Maria Elvira Garcia, Colombia
17. Sandra Costi, Argentina
18. Josefina Pèrez Rodriguez, Mexico
19. James Gardner, USA
20. Urs Eiholzer, Switzerland

21. Lantz Yap Chee Seng, Malaysia
22. Susanne Blichfeldt, Denmark
23. Berit Otterlei, Norway
24. Ragnhild Øverland Arnesen, Norway
25. Pawerisa Assawasoonnet, Thailand
26. Duangrurdee Wattanasirichaigoon, Thailand
27. Nitcha Khunin, Thailand
28. Maria Punturiero, Australia
29. Deborah Banks, Switzerland
30. Charlotte Høybye, Sweden
31. Lutz Lämmer, Germany
32. Linda Gourash, USA
33. Maria Libura, Poland
34. Michelle Torbert, USA
35. Neil Gumley, Australia
36. Constanze Lämmer, Germany
37. Monika Fuhrmann, Germany
38. Engela Honey, South Africa
39. Molelekeng Sethuntsa, South Africa
40. Gary Brennan, Ireland
41. Jane Cox, Ireland
42. Joan Gardner, USA
43. David Gordon, USA
44. Janice Fraser, Canada
45. Michael Pethe, Switzerland
46. Maria Huber, Austria
47. Juana Liceras, Canada
48. Estela Garcia, Canada
49. Ella Maria Llanos, Australia/Colombia
50. Nick Burke, Australia
51. Paraskevi Farmaki, Greece
52. Zurab Abjandadze, Georgia
53. Damien Jones, Australia
54. Nicolas Ruge, Colombia
55. Nayhibe Beltran, Colombia
56. Agnes Hctor, UK

4. Minutes of the two Extraordinary General Meetings held in October to arrange the transfer of structure and assets from the old IPWSO to the new charity

The EGMs were held on 14th October 2019 and the outcome is minuted below from David Gordon:

Mr President/ EGM Chair As the duly appointed election officer for the EGM, I hereby certify:

1. No member has requested to attend the meeting.
2. More than 75% of the members entitled to vote have voted. A quorum has been reached.
3. All votes were in favour of all the motions before the EGM. There were no abstentions and no votes against.
4. All motions are therefore carried.

David Gordon Legal Advisor to IPWSO

This was confirmed at a meeting of the President, Vice President and Legal Advisor on 14th October 2019

The General Assembly ratified this decision on the recommendation of the Board.

5. Minutes of previous General Assembly held on 24th July 2016 in Toronto

The minutes were approved.

6. President's Report

Tony Holland reported on activities since the current Board took over at the General Assembly held in Toronto in 2016.

Governance

This year (2019) IPWSO became established as a Charitable Incorporated Organisation (CIO) registered with the Charities Commission of England and Wales. This is the first General Assembly to occur since then. This year we also opened bank accounts in the UK and at a recent EGM agreed that funds could be transferred from the previous accounts held in Italy to those in the UK in Sterling, US \$ and Euro.

In terms of staffing Agnes Hoctor based in Cambridge, UK was appointed to a temporary position to support the Cuba Conference and now will take over as Communication and Membership Manager as Linda Thornton is retiring. Tony gave his thanks to Linda on behalf of the whole of IPWSO for her many years of work and integral role in the success of the organisation.

Membership

The associations in Malaysia and Thailand have joined IPWSO as full members. Cyprus has joined as an associate member. We now have:

- 35 subscribed countries
- 72 associate countries

New developments

- In 2017 we established IPWSO advisors, a group of individuals who are able to give us detailed advice on particular areas of specialist knowledge (see our website for their names)
- In 2017 Joan Gardner and Susie Cassidy established the Friends of IPWSO (USA), Marilyn Dumont-Driscoll will continue to attend Board meetings in a new role linking Friends to the Board.
- In 2018 with the support of Norbert Hödebeck-Stuntebeck and Hubert Soyer German Friends of IPWSO was established with Karsten Freischem as the Chair.

Fundraising

Marguerite Hughes has chaired our fundraising committee and has taken on the challenge to diversify our sources of funding, which currently include:

- Membership fees and donations from Member countries
- Individual donations

- Friends of IPWSO (USA)
- Conference sponsors: main sponsors being Pfizer and Millendo, with support also coming from Levo, Zafgen, the Pontifical Commission for Latin America and many others (for a full list of sponsors see the conference booklet).

Activities

- We have given support to individuals with PWS including funding the free diagnostic testing at BIRD Institute, Italy – over 500 tests have now been funded.
- Our Clinical and Scientific Advisory Board continue to respond to clinical enquiries from around the world on a range of complicated matters relating to care and treatment.

We have attended conferences to promote knowledge about PWS within professional groups, most recently at:

- ESPE, Vienna
- European Congress of Endocrinology, Lyon
- IASSIDD conferences in Bangkok, Athens, Glasgow

Workshops, attendance of IPWSO members at country events, and financial support to national meetings, venues including:

- Australia
- Brazil
- Bulgaria
- China
- Chile PPCB (over 200 families)
- Colombia
- India
- Morocco
- Romania
- Vietnam

In 2018 the PPCB hosted its conference in Munich which also included a Board meeting to steer the future direction of IPWSO.

Organisation of our international conference in Cuba, November 2019: Thanks to funding from the Friends of IPWSO (USA) we were delighted to offer travel scholarships to 11 exceptional candidates from around the world including (see the website for their reports after the conference):

- Argentina
- Bulgaria
- Colombia
- El Salvador
- Georgia
- India
- Kenya
- Mexico
- South Africa

Publications

We have continued to have a strong commitment to publishing new materials and guidance on our website including many in different languages:

- Preparations of new materials (through our committees, CSAB and Famcare).
- Translation of existing materials – most recently with a strong emphasis on Spanish language.

Contributions at an International level

We have taken part in activities through the:

- Rare Diseases International
- Global Genes
- Clinical Trials Consortium

Jean Phillips-Martinsson

IPWSO founder Jean Phillips-Martinsson sadly lost her son Anders this year. Anders had PWS and was the inspiration behind Jean's work in the field and the establishment of IPWSO. She has approached IPWSO about setting up a fund and we will be able to announce more about this in 2020.

Project Echo

IPWSO is heavily involved in Project Echo which we will develop in 2020 through two strands, one to connect local associations together and one based around healthcare needs.

7. Treasurer's Report

Hubert Soyer reported that IPWSO's bank accounts had now been moved to the UK. We now hold around GBP 60,000, Euro 75,000 and USD 28,000.

The treasurer thanked members and supporters for their financial support over the past 3 years. The Cuba conference costs will be covered from registration fees and sponsorship.

8a. Clinical & Scientific Advisory Board (CSAB)

Dan Driscoll reported that the CSAB was made up of 14 physicians, experts from around the world who met on a monthly basis. The CSAB responds to enquiries from families and professionals around the world. The Board also produces guidance documents, for example on ageing, many of these papers have been translated and made available online.

The CSAB also responds to topical issues for example producing a rapid response to a journal article from an endocrinology group on growth hormone.

Dr Driscoll reported that the Clinical and Scientific conference had been very successful, with cutting-edge research presented and many fields of expertise represented. The CSAB wants to foster a collegial approach and Dr Driscoll was pleased to see many delegates staying on to attend the Parents' conference. Looking forward to 2022 Dr Driscoll hoped the conference would be hosted in an attractive venue with an accessible hotel/venue, to avoid clashing with other PWS conferences and with good IT support.

8b. Professional Provider Caregiver Board (PPCB)

Norbert Hödebeck-Stuntebeck reported that the PPCB is made up of 10 committee members representing caregivers in 7 countries. He thanked the members for their work over the past 3 years. The list of members can be viewed on the IPWSO website.

The PPCB has been involved in organising a number of events since the last conference. In 2017 they held a joint event in Chile which was very successful. They also hosted an IPWSO caregivers' conference in Munich in 2018 which was attended by delegates from around the world.

The PPCB was heavily involved in planning for Cuba 2019 and had a successful two days of conference with many delegates also staying on for the Parents' conference.

The committee are planning a caregivers' conference for 2021 to be held in Berlin.

8c. Famcare (Family Care committee)

Georgina Loughnan reported that Famcare's main role is to write articles and provide advice for families concerning the management of PWS both at home and in care. Many of these articles have now been translated into a range of languages.

Georgina thanked Linda Thornton for her support in particular developing the range of translated articles. Georgina is now retiring from her Famcare role and passing the Chair over to Amalia Balart.

She reported that it has been a pleasure to work on the Parents' programme for Cuba and she was delighted that the conference was well attended by families from around the world including many from Cuba.

Georgina has also represented Famcare and IPWSO at various conferences over the past 3 years which has been very productive. She thanked Tony Holland for his work and support.

9. Election of President and Board members

Marguerite Hughes presented the slate of candidates for election and each member spoke a few words of introduction (François and Marcello sent their apologies and Marguerite Hughes introduced on their behalf):

New members:

- Craig Moore (Australia)
- Maria Libura (Poland)
- Marcello Schutzer (USA)
- François Besnier (France)
- Lynn Garrick (USA)
- Kate Woodcock (UK)

Members standing for a second term:

- Tony Holland (UK), IPWSO President
- James O'Brien (Australia)
- Verena Gutmann (Austria)
- Amalia Balart (Chile)

No objections were raised to the election of these candidates and they were duly elected for a term of 3 years.

10. Bidding to host the next IPWSO conference to be held in 2022

- Presentation from India
- Presentation from Ireland
- Presentation from Malaysia
- Presentation from Thailand

The four associations presented an overview of the venue and some of the proposed logistics for the conference and were asked questions from the floor. Then the delegates present were asked to vote.

11. Any other business

Tony Holland extended his thanks to the outgoing Board and presented them with leaving gifts: June-Anne Gold, Mariona Nadal, Marilyn Dumont-Driscoll, Georgina Loughnan, Marguerite Hughes and Hubert Soyer.

12. Announcement of venue for the 2022 IPWSO conference

Tony Holland announced that Ireland would host the 2022 conference. He congratulated their team and thanked all the bidding countries for their contribution and looked forward to working with all the countries in the future.