

IPWSO Conference Guidelines

Introduction

Thank you for your interest in hosting the 13th IPWSO conference, which will take place in 2028.

The main aim of the conference is to enable parents, scientists, professional caregivers and people with PWS to share information, meet others, and learn about the latest research and management techniques.

The IPWSO Conference is held every 3 years and has taken place in 11 different countries to date: Netherlands (1991), Norway (1995), Italy (1998), USA (2001), New Zealand (2004), Romania (2007), Taiwan (2010), UK (2013), Canada (2016), Cuba (2019) and Ireland (2022). The 2025 IPWSO conference is scheduled to take place in the USA.

While every IPWSO Conference is expected to lead to benefits for people with PWS and their families throughout the world, IPWSO Conferences can also bring particular benefits to the host country and region:

- Hosting an IPWSO conference brings worldwide experts in every aspect of PWS to the host country, providing the doctors, professional caregivers, families, and others who support children and adults with PWS with a valuable opportunity to hear the latest information and advice;
- Host countries may use the IPWSO Conference to gain media coverage, which could result in new diagnoses or more families making themselves known to the national association;
- Hosting an IPWSO Conference can strengthen the host country's links with other countries and other national PWS associations.

Conference Format

The current IPWSO Conference format comprises a series of programmes that typically take place over 5 consecutive days, usually from Wednesday to Sunday.

- The Clinical and Scientific Programme takes place over two full days, usually Thursday and Friday.

- The Professional Caregivers Programme takes place over two full days, usually Thursday and Friday.
- The Parents Programme takes place over two full days, usually Saturday and Sunday.
- The Programme for Children with PWS takes place over two days, usually Saturday and Sunday. This programme may also include siblings.
- The Programme for Adults with PWS takes place over two days, usually Saturday and Sunday.
- The 2022 Conference featured a one-day Interdisciplinary Programme for Allied Health Professionals and Educators.
- Various workshops and pre-conference meetings typically take place on Wednesday. These are usually invitation-only events.
- The IPWSO General Assembly, which is a formal meeting of its member countries, usually takes place at the end of the Parents Programme on Sunday afternoon.

In addition to the programmes, the Conference typically has a Celebration or Gala dinner on Friday night and a Welcome Reception on Wednesday night. Additional social events may be added at the discretion of the hosts.

The IPWSO conference is organised as a face-to-face event. This format has been chosen to maximise networking opportunities and delegate interactions. However, you should consider whether an online component might be possible to broaden audience reach. This could, for example, take the form of pre-recording or live recording sessions. These could then be made available to a virtual audience either live or on a date after the conference. Special consideration should be given to local and international privacy law and publishing copyright.

The main conference language is always English. Professional interpretation into one or more other languages is encouraged where possible.

If you wish to propose any changes to the current format, you should discuss this with IPWSO before submitting your bid.

Planning and Organising the Conference

IPWSO usually retains overall responsibility for organising the Conference, but does so in partnership with the host country organisation. After a host country has been selected, a Memorandum of Understanding (MOU) will be drawn up and signed by both parties so that

they are clear about their responsibilities and the timeframes in which different actions need to be completed.

It is expected that IPWSO and the host country organisation will conduct their relationship on the basis of good faith and respect for each other's views. It is expected that there will be regular, open and friendly cooperation between IPWSO and the host country organisation in the planning and carrying out of the Conference. Both parties will be expected to make each other aware of any significant challenges if they arise.

The organisation of the Conference will be primarily managed by Programme Committees and overseen by one overall Conference Committee.

Each programme will have its own Programme Committee comprising representatives nominated by IPWSO and the host country organisation. There are typically 1 or 2 representatives from the host country organisation on the Programme Committees for the Clinical and Scientific, Professional Caregivers, and Parents Programme. The majority of members of these committees will come from IPWSO's Clinical and Scientific Board, Professional Providers and Caregivers Board, and FamCare (Family Care) Board. There are typically more host country organisation representatives on the Programmes for Children and Adults with PWS and these programmes are generally led by the host country organisation.

Each Programme Committee will be responsible for designing the programme content, liaising with speakers, and managing the programme budget. Each Programme Committee must submit its recommended programme, its proposed budget spending, and its room and audiovisual requirements to the Conference Committee for approval.

The Conference Committee is responsible for overseeing all aspects of the Conference. Membership of the Conference Committee will comprise representatives from both IPWSO and the host country organisation. It will include at least one representative from each Programme Committee, at least one host country organisation representative, and usually the IPWSO Conference Manager, President and CEO.

The frequency of Programme Committee and Conference Committee meetings will be determined by their membership. Meetings will typically be held by Zoom. Minutes or a written record of decisions taken will be retained for each meeting.

Division of Responsibilities

- The host country organisation is responsible for selecting a venue that meets the requirements of the Conference (see below for more details) and for liaising directly with the venue about all aspects of the conference logistics.
- The host country organisation is responsible for organising the social events associated with the Conference (Gala, Welcome Reception and any other events).
- The host country organisation is responsible for identifying pre- and post-conference visitor options including tours and travel agency services.
- The host country organisation is responsible for identifying and reserving sufficient accommodation to meet the needs of the delegates.
- The host country organisation is responsible for organising interpretation if this is being provided.
- The host country organisation and IPWSO will together consider issues relating to the recording and online sharing of elements of the conference.
- IPWSO is responsible for building the Conference website pages and registration platform and for handling registrations and payments from delegates.
- IPWSO is responsible for marketing the Conference internationally.
- The host country organisation is responsible for marketing the Conference within their own country and may also be asked to assist with promoting the Conference regionally.
- IPWSO is responsible for the overall Conference budget but will liaise closely with the host country organisation in relation to the budget.
- IPWSO will design a logo for the Conference in conjunction with the host country.
- Depending on the requirements of the country, IPWSO and the host country organisation will agree who is responsible for insurance for each element of the Conference.
- The host country organisation is responsible for ensuring that all local laws and IPWSO policies are adhered to in relation to child protection and safeguarding. The Chairs of the Programme for Adults with PWS and the Programme for Children with PWS will be required to submit details to the Conference Committee of the safeguarding measures that will be in place.
- IPWSO and the host country organisation will together consider whether volunteers are needed for the Conference and who might fulfil these roles.
- Most IPWSO Conferences are organised around a theme (e.g. “East meets West” in Taiwan, “From Research to Practise” in the UK, and “Improving Understanding Across the World” in Cuba). It is the responsibility of the host country organisation to propose a theme as part of their bid.

Number of delegates

The number of delegates will depend on factors including:

- the accessibility of your country and travel costs for people from other countries;
- the number of families and professionals in your country who attend;
- external circumstances (e.g. a pandemic, or other conferences that are taking place that year).

For the purposes of preparing a bid, you should expect between 300 and 750 delegates to attend across the 5 days. A majority of delegates typically only stay for one Programme (i.e. for 2 days).

Venue

You are required to identify a suitable venue before making a bid. The venue does not have to be a purpose-built conference centre. In some cases universities or individual hotels can offer sufficient space and services at a reasonable price. The venue should have good transport links and be within easy reach of an international airport. It should be moderately priced to keep the conference as inexpensive as possible.

Ideally, there should be on-site accommodation but, if this is not possible, ensure there are accommodation providers and restaurants within easy reach. Bear in mind that hotel rooms will need to accommodate parents with children, as well as couples and those attending on their own. If possible, ensure that nearby hotels or other forms of accommodation will suit a range of budgets.

You should also ensure that there is disabled access for those using wheelchairs, or who have other forms of disability.

To host a Conference in its current format, your venue must have the following available **as a minimum**:

- 2 large lecture theatres (1 to hold a minimum of 400 people and the other to hold a minimum of 300 people)
- 3 medium sized lecture theatres (each to hold a minimum of 120 people)
- 4 breakout rooms (each to hold a minimum of 50 people)
- At least one foyer/large room for registration, display booths and information tables
- One large room (or two smaller rooms) to accommodate up to 100 poster displays
- Two meeting rooms for people wishing to hold smaller meetings (Up to 20 people)

- A lockable room for storage
- Facilities to host the programmes for people with PWS (depending on the type of programme you are planning)
- Area/rooms for refreshments and lunch.

Costs and Conference Budget

Every effort should be made to ensure that the Conference is accessible to people from around the world. This necessitates keeping costs as low as possible.

To encourage attendance from around the world, registration fees are set at a level that is insufficient to cover the full costs associated with the Conference. Therefore, it is essential that sufficient sponsorship is raised or donations are received to bridge the gap between registration income and conference costs.

IPWSO and the host country organisation will work in partnership in relation to all elements of finance and budgeting. It is expected that both parties will strive to raise as much money as possible to ensure the smooth running of the 2028 Conference and to build reserves to underwrite future IPWSO Conferences

Conference income is received from 4 main sources:

- Registration fees;
- International sponsorship and donations;
- National sponsorship and donations secured in the host country;
- In some cases, a donation from the host country organisation.

Costs are mainly associated with:

- Venue rental;
- Catering;
- Financial supports to speakers;
- Materials for delegates;
- Audio visual support;
- Conference recording and photography;
- Interpretation, if this is provided;
- Social event costs (e.g. Gala Dinner and Welcome Reception);
- Services and materials required with the Programmes for Adults and Children with PWS.

IPWSO is responsible for setting the budget, setting the registration fees, covering the costs of the agreed expenditure and, where possible, securing international sponsorship to support the Conference costs. The host country is responsible for contributing to the costs of the Conference (through donations and/or securing sponsorship in their country) and for identifying a cost-effective venue and services.

As part of the preparation of a Memorandum of Understanding between IPWSO and the host country organisation, an agreement will be reached as to which party will sign contracts with the venue and other local service providers.

If a surplus is achieved this will be used by IPWSO to underwrite future IPWSO Conferences.

Bidding for the conference

Bidding for the 2025 Conference takes place into 2 stages.

Stage 1. Interested host country organisations submit a bid for consideration by IPWSO by 14 February 2025. Please talk to us before submitting your bid so we can work together to maximise its potential.

Stage 2. All bids that are financially viable and meet the logistical requirements set out by IPWSO are circulated to IPWSO's members for consideration. You will have an opportunity to present your bid in person at the General Assembly held during the Conference in Arizona, USA in June 2025 (date of General Assembly to be confirmed). In the event of more than one country bidding, a vote will be held at the General Assembly with paid-up member countries having one vote each. The bidder that receives the most votes is the winner.

Stage 1

The purpose of submitting a bid to IPWSO in advance of the General Assembly is to enable IPWSO and the host country organisation to clarify any points that are unclear, to give both parties an opportunity to raise any concerns, and to work towards a situation where hosting the Conference in the proposed country will best meet both the needs of that country and IPWSO. This stage will involve at least one meeting between IPWSO and the bidder as well as email correspondence.

If during this process the host country organisation concludes that it is not feasible for them to host the Conference, or that doing so will not meet their needs, they are entitled to withdraw their bid before it is circulated to IPWSO's members for consideration at the General Assembly. They are also entitled to modify their bid based on their discussions with IPWSO.

If, having reviewed the Bid and discussed the issues with the Bidders, IPWSO concludes that the Conference is not financially or logistically viable in that country or venue at that time, it will not circulate the bid to IPWSO's members for consideration at the General Assembly.

Please ensure that your bid answers the questions that appear in Appendix 1 and that you complete the blue sections of the Budget Template that is circulated along with this document.

Stage 2

Once you have received confirmation from IPWSO that your bid meets the requirements necessary for it to be presented at the General Assembly, you should prepare a poster and submit it to IPWSO by 20 May 2025. This will be circulated to IPWSO members in advance of the Conference, displayed at the Conference venue in Arizona, and displayed on IPWSO's website. You should also prepare a 10-minute PowerPoint presentation, which you will be expected to deliver to IPWSO's members at its General Assembly. You should also be prepared to answer questions from delegates.

The Poster and PowerPoint represent your opportunity to showcase your bid. We recommend you include:

- Information about your organisation
- Where you are proposing to hold the conference
- Accommodation options for delegates
- Travel links
- Local attractions
- Any special programme items you plan to organise
- Any plans for interpretation
- Any plans to record the conference or share conference materials after the event

As member countries will vote based on the information in your presentation bid, it is important that you only commit to conference features that you are sure you can provide.

Contact us

If you have any questions about bidding for the 2025 conference, or would to meet us to discuss any issues before submitting a bid, please contact Nora McNairney, on nmcnairney@ipwso.org

All completed bids should be emailed to Nora by 14 February 2025.

Appendix 1

As part of your bid, we ask that you complete in US\$ the sections highlighted in blue in the attached Excel Budget Template. All other sections will be completed by IPWSO.

We also ask that you also provide information on the following issues.

1. Details of your Organisation, including the number of members and active volunteers, and any previous conferences or events you have organised.
2. Details of the proposed venue including the following.
 - Number of meeting rooms and their capacities.
 - Technical details of the venue – e.g. is WIFI available throughout?
 - Terms and Conditions – e.g. the payment schedule required by the venue and details of whether deposits are refundable if the conference has to be postponed or cancelled.
 - The costs associated with the venue. The attached Budget Template provides details of the estimated room requirements for each day and we ask that your pricing be based on these requirements.
 - Catering options and costs offered by the Venue. Terms and Conditions associated with catering - e.g. the payment schedule, details of whether deposits will be refundable, details of whether we will be charged for a minimum of delegates regardless of attendance.
3. Details of the accommodation that will be available for delegates, including the number and types of rooms, the cost of accommodation, and the Terms and Conditions that apply to accommodation bookings. These include the cancellation policy for individual delegates and whether a minimum number of bookings are required to secure the rates quoted.
4. Details of the transport links to the venue, including how close the nearest international airport is to the venue, and how people could travel from the airport to the venue.
5. Details of the dates that you are proposing for the Conference. IPWSO Conferences generally take place in July or August, but other times of the year may be considered to meet local needs.
6. With the exception of a small number of key organisers from the host organisation whose registration fees will be covered from the Conference budget, all other delegates from the country will be expected to pay full registration fees. These fees will be set by IPWSO taking into account the costs and anticipated sponsorship for the Conference. For example, the 2022 IPWSO Conference registration fees were €200 for a parent to attend the family programme and €340 for a professional to attend the Clinical and Scientific Programme. The 2025 IPWSO Conference registration fees are \$250 for a parent to attend the family programme and \$450 for a professional to attend the Clinical and Scientific Programme. Taking into account the registration fees and other costs associated with attendance, how many family members and professionals would you expect to attend the Conference from your country?

7. Details of whether you plan to interpret the Conference and if so the language/s involved. For the purposes of estimating interpretation costs the attached Budget Template lists the number of sessions for which we would expect interpretation to be required each day.
8. Details of whether you plan to pre-record or record any or all of the sessions.
9. Details of the proposed content for the Programmes for Adults with PWS and Children with PWS. Please specify how many places you feel you could offer on these programmes and how many people from your country you would expect to attend. Please also confirm whether to wish to include siblings in these programmes.
10. Details of the social events associated with the Conference, including the Welcome Reception and Gala Dinner. You are welcome to add other social events if you wish.
11. Details of how you would obtain sponsorship or fundraise locally.