

# Guidance on Preparing an Expression of Interest for the 2027 IPWSO Caregivers' Conference

#### Introduction

Thank you for your interest in hosting the 7<sup>th</sup> IPWSO Caregivers' Conference, which will take place in 2027.

Professional providers and caregivers are often integral to the health and well-being of people with Prader-Willi syndrome (PWS), especially those living outside the family home. The main aim of the IPWSO Caregivers' Conference is to provide a collaborative forum where professional providers and caregivers can access and discuss the latest research and guidance about topics essential to care provision. Hosting the Conference can bring particular benefits to the local host and country.

This Conference is designed for anyone with daily or occasional involvement as a professional caregiver of people with PWS. People working in a supportive role with a national PWS association, and those who have an interest in establishing a care setting for people with PWS, are also welcome.

## **Conference Format**

This Conference typically takes place over three days and comprises both lectures and workshops that are hosted in a collaborative atmosphere where professional caregivers can exchange practice-driven knowledge and actively contribute their own experiences to enhance the care they provide and develop new methods of support.

In addition to the lectures and workshops, the Conference usually features a celebration dinner on one evening. Additional social events may be added at the discretion of the local hosts.

The IPWSO Caregivers' Conference is organised as a face-to-face event to maximise networking opportunities and peer learning. Local hosts may wish to broaden the Conference's reach by including an online component. This could, for example, take the form of pre-recording or live recording some sessions.

The main Conference language is English. Professional interpretation into one or more other languages may also be needed.

# **Planning and Organising the Conference**

IPWSO retains overall responsibility for organising each Caregivers' Conference but does so in partnership with a local host. A local host could be a national PWS association or an organisation that provides services to people with PWS.

After a local host has been identified, 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.

The organisation of the Conference will be primarily led by IPWSO's Professional Providers and Caregivers Board in collaboration with the local host.

# **Division of Responsibilities**

- The local host 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 local host is responsible for organising the social events associated with the Conference (Celebration Dinner, and any other events).
- The local host is responsible for identifying pre- and post-conference visitor options including tours and travel agency services.
- The local host is responsible for identifying and reserving sufficient accommodation to meet the needs of the delegates.
- The local host is responsible for organising interpretation if this is being provided.
- The local host 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 local host 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 local host in relation to the budget.
- IPWSO will design a logo for the Conference.
- IPWSO is responsible for insurance for each element of the Conference.
- IPWSO and the local host will together consider whether volunteers are needed for the Conference and who might fulfil these roles.

# **Number of delegates**

The number of delegates will depend on many factors. For the purposes of preparing the Expression of Interest estimates, assume that 100 delegates will attend for the full three days.

#### Venue

The Conference venue should have good transport links and be within easy reach of an international airport. It should be moderately priced.

Ideally, there should be on-site accommodation but, if this is not possible, ensure there are accommodation providers and restaurants within easy reach.

The venue should provide disabled access for those using wheelchairs, or who have other forms of disability.

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

- 1 large room with capacity for at least 130 delegates
- 3 breakout rooms with capacity for at least 30 delegates
- One foyer/large room to accommodate the registration desk, up to 10 posters, and up to 6 exhibition tables
- Area/rooms for refreshments and lunch. It is possible that a small number of people
  with PWS may attend the Conference. If so, it will be necessary for food to be
  managed taking their needs into account.

# **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 usually 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 local host will work in partnership in relation to all elements of finance and budgeting.

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 local host.

## 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. Celebration Dinner);

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 local host is responsible for identifying a cost-effective venue and services and, where possible, contributing to the costs of the Conference.

As part of the preparation of a Memorandum of Understanding between IPWSO and the local host, 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 activities.

# **Expressing Interest in Hosting the 2027 Caregivers' Conference**

If you are interested in hosting the 2027 Caregivers' Conference, please submit an Expression of Interest by answering the questions in Appendix 1 and completing the blue sections in the attached budget template.

Please return this information to <a href="mailto:scordner@ipwso.org">scordner@ipwso.org</a> by 27 March 2026.

A meeting will be arranged with you once the IPWSO team has reviewed your Expression of Interest.

The purpose of this meeting will be to enable IPWSO and your organisation to clarify any points that are unclear, raise any concerns, and work towards a situation where hosting the Conference in the will best meet the needs of your organisation and IPWSO.

If more than one Expression of Interest is received, a venue will be selected by the PPC Board based on the following criteria:

- Budget
- Location accessibility for delegates
- Venue
- Where possible preference will be given a country that has not already had the opportunity to host a previous IPWSO conference.

#### **Contact us**

If you have questions or would like to discuss any issues before submitting an Expression of Interest, please contact Shelly Cordner at scordner@ipwso.org

All completed Expressions of Interest should be emailed to Shelly by 27 March 2026.

# **Appendix 1**

To Express Interest in hosting the 2027 Conference, please complete in US\$ the sections highlighted in blue in the attached Excel Budget Template. All other sections will be completed by IPWSO.

Please also provide the following information.

- 1. Details of your organisation and any recent conferences or events it organised. If your organisation is not a PWS Association, describe your organisation's relationship with the national PWS Association.
- 2. Details of the proposed venue including the following.
  - Number of meeting rooms and their capacities
  - Technical details of the venue e.g. WIFI and AV
  - 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.
  - Costs associated with the venue based on the room numbers described above.
  - Catering options and costs offered by the Venue. Terms and Conditions associated with catering e.g. the payment schedule, details of whether deposits would be refundable, details of whether IPWSO would be charged for a minimum of delegates regardless of attendance.
- 3. Details of the accommodation that would 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 Caregiver Conferences generally take place between May and September, 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 local host organisation whose registration fees may be covered from the Conference budget, all other delegates from the host 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 2025 Caregivers' Conference registration fees were \$375.00 (Early Bird)/\$425.00 (Standard). Taking into account the registration fees and other costs associated with attendance, how many people 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.
- 8. Details of whether you wish to pre-record or record any or all of the sessions.
- 9. Details of the social events associated with the Conference, including the Conference Dinner.
- 10. Information about whether your organisation would be able to obtain sponsorship or fundraise locally.