IPWSO
International
Prader-Willi Syndrome
Organisation

www.ipwso.org

“WITH US” NOT “ABOUT US”

INCLUSIVE MEETINGS FOR PEOPLE WITH PRADER-WILLI SYNDROME

Contents

The IPWSO People with PWS Committee

The guidance in this document has been developed by the IPWSO People with PWS Committee, and the people with PWS we work with. The committee is a group of international experts supporting people with PWS to advocate for themselves to ensure their voice is heard in their local communities, National Associations and IPWSO. We work alongside people with PWS to determine and establish the best platforms to express their own needs and wishes, and to exchange ideas on their interests and personal experience, quality of life and wellbeing with each other, with PWS professionals, and with IPWSO.

Introduction

MEETINGS FOR PEOPLE WITH PWS

As human beings we all share several fundamental needs that drive much of our behaviour. Having these needs met is essential for our health, wellbeing and happiness. These needs include: The need to belong – to feel safe and comfortable with certain other people or in certain places; the need to be autonomous – to feel like we have control over our own life; and the need to matter – to feel like we have a purpose, are listened to and respected. Disability, such as that resulting from living with Prader-Willi syndrome, can often disadvantage people and creates barriers to meeting these needs. Consciously engaging people living with Prader-Willi syndrome in inclusive meetings can help to overcome these barriers.

Community, relationships, and peer-to-peer support are vital to one's mental health and well-being. Like anyone else, people with PWS need a forum to express their ideas, opinions and feelings. This can be empowering, foster a sense of purpose, and help develop skills to advocate for themselves and others. But we know, just like everyone else, everyone with PWS is different; differing levels of social skills and cognitive abilities should be considered when planning a meeting for people with PWS, so that everyone feels comfortable and encouraged to participate.

MEETINGS FOR PEOPLE WITH PWS

Any Prader-Willi syndrome organisation, from big associations to small online forums, must be conscious of the need to include the voices of people with PWS in their work. IPWSO’s network includes examples of many successful meetings and social activities tailored for people with PWS all over the world. We’ve collaborated with organisers in Austria, Australia, Germany, Ireland, Malaysia, UK, USA, and more to help us understand best practice in developing and running a PWS group . We’re pleased to share some of this advice here, and hope it helps anyone wishing to improve their existing meetings with people with PWS or, excitingly, those wishing to start a new PWS group.

> “THE ACTIVE PARTICIPATION OF PEOPLE WITH PWS SHOULD BECOME AN INTEGRAL PART OF FUTURE CONFERENCES. HEARING THE VOICES OF ADULTS WITH PWS IN LIMERICK (IPWSO 2022 CONFERENCE) WAS POWERFUL AND WILL FORM THE BASIS OF PWSAI STRATEGIC PLANNING INTO THE FUTURE.”
>
> -GARY BRENNAN
>
> NATIONAL DEVELOPMENT MANAGER FOR PRADER-WILLI SYNDROME ASSOCIATION IRELAND (PWSAI)

CASE STUDY: OUR WAY OF LIFE AUSTRALIA

The Australian OWLA (Our Way of Life – Australia) group has been running since August 2021. The concept was adapted from the model used by PWSA UK. The idea behind this group was to build the capacity of the people living with PWS to ***"speak up and speak out"****, enabling their voice to be heard.*

It is a virtual meeting involving people from different states in Australia. One man from Malaysia also joins our group when possible. The level of intellectual ability varies from moderate to mild and the ages are from 18 – 46 yrs.

OWLA discussion and presentation topics have included:
leisure activities, employment, mental illness, what members like about living with PWS, exercise, life during COVID lockdown, spreading the knowledge of PWS to others, advocacy for people with PWS by people with PWS, research into PWS, travel, bullying at school, friendships and relationships.

People in the group have shared that they do not consider themselves to be disabled – they just have an appetite problem. One man expressed that PWS has made him who he is.

CASE STUDY: OUR WAY OF LIFE AUSTRALIA

Main points of interest from the OWLA groups so far:

1. People with PWS are very good at maintaining meeting protocol, once they have practised it – listening, not speaking when others are speaking. They do still require some facilitation.

2. They have great ideas when they are listened to:
    - When one man with PWS spoke about his mental illness and the fact that he does not cope well with a lot of noise, another man with PWS suggested he buy “noise-cancelling head phones” to wear when he is in a noisy place.
    - When one lady suggested “more people need to know about PWS!”, one man came up with the idea of “a QR code be created to add to a necklace or wristband for people with PWS to wear, to explain PWS”.
    - One lady suggested PWS Australia look into developing food specifically for people with PWS to buy in the shops (a bit difficult, but a great idea!)
    - One woman with PWS and one man with PWS offered to go into schools to speak to students about PWS to try to prevent bullying of students with PWS.

3. People with PWS really enjoy meeting with other people with PWS and the age or intellectual ability of those they meet is not bothersome to them. People in the group are now much more confident and comfortable with each other.

CASE STUDY: OUR WAY OF LIFE AUSTRALIA

In December 2022 a 2-day OWLA conference was held. People with PWS and either a family member(s) or a support provider stayed at a conference centre in a beachside suburb of Sydney.

17 people, including 3 facilitators attended. Powerpoint presentations were given by individuals with PWS, then discussed by the group. The different topics were chosen by the presenter who had some assistance in organising their presentations.

***Pictured: OWLA group members at 2022 conference**.*

Participants had dinner, then a film night at the end of the first day, and visited the local zoo during the second day. The weekend finished with a review of the conference, deciding what went well and what could be improved for a future conference.

SEE OWLA MEMBERS IN ACTION...

Short films of the participants with PWS were recorded during the December 2022 conference. Further recordings will be made during the 6th Asia Pacific PWS Conference in August 2024. These films are available on the PWS Australia YouTube channel.

PEOPLE WITH PWS GIVE THEMSELVES A VOICE

Christian Blohm's presentation, "People with PWS Give Themselves a Voice," delivered at the 6th International Prader-Willi Syndrome Caregivers' Conference in May 2024, highlights the work of a group for people with PWS in Germany, aimed at empowering individuals with PWS to actively participate in decisions affecting their lives. The group gives particpants the support they need to share their own thoughts, feelings, and choices. It's about building their confidence, helping them communicate better, and making sure their voices are heard.

Pictured: Christian Blohm presents at the Conference, 2024.

- *Real involvement: People with PWS can and should play an active role in decisions that affect them.*
- *Support is key: With the right tools and structure, they can express themselves more clearly and confidently.*
- *Big benefits: The project led to better communication, more self-confidence, and a stronger sense of belonging.*

Overall, it shows how powerful it can be when people with PWS are given the space and support to speak for themselves.

Watch the presentation,
People with Prader-Willi syndrome give themselves a voice: Requirements and solutions.

WHY? THE OBJECTIVES OF YOUR GROUP

Your organisation may choose to start a PWS group for lots of different reasons.
For example:

- To support your network of people with PWS;
- To connect those who may feel a sense of isolation, or loneliness;
- To help people with PWS practice and feel empowered to speak in a public or social setting;
- To provide a community, peer-to-peer support and advice;
- To help empower people with PWS to support their peers;
- To provide a meaningful forum for people to have their voices heard;
- To generate ideas on how people can raise awareness of PWS;
- To provide training courses or teach life and employment skills;
- To determine with people with PWS how they can play a role in global advocacy;
- To include people with PWS in the work of your organisation;
- To learn what it is like to have PWS from people with PWS;
- To include people with PWS in the work of IPWSO.

It’s likely you’ll have already asked the people with PWS that you know about what they would like to achieve as part of a group, and what they might like to talk about.

Whatever your reasons for starting a group, we recommend making it clear what the objectives of the group will be, so that everyone who joins knows why they might want to attend, and what they can hope to achieve together with others.

WHO? SUPPORT AND INCLUSIVITY

Moderators

To safeguard vulnerable people in the group, and to foster a harmonious environment, a person who is trained and experienced in supporting people with PWS should host and moderate the meetings. You may also choose to have a second host to support this person.

Some of the basic principles of communicating with people with PWS include:

- Use simple, straightforward language - use less words and shorter sentences;
- Don’t speak too quickly;
- Give the person time and space to think and formulate their response.

Our experts found that with time, more established groups need less support from moderators.

Mexico, Fundación Mariajosé, 6th annual PWS family conference, 2022

WHO? SUPPORT AND INCLUSIVITY

Group leaders and members

The groups we consulted with considered the many different circumstances for people with PWS when considering who would take part in group meetings.

- No one should be eating or drinking during the meeting;
- Some will have higher levels of cognitive thinking than others;
- Some people are able to verbalise or express themselves more clearly than others;
- Your group structure should be inclusive of all levels of abilities;
- Some may be likely to experience anxiety in a group setting;
- Some live in group homes, others live in the family home;
- Some will feel more comfortable speaking on Zoom or on the telephone, rather than in-person;
- Be aware of personal privacy, for example sharing last names is not needed for the meetings when first names will do;
- Many will benefit from the support of a caregiver, or caregivers, joining the meeting with them. Your country may have regulations with regards to safeguarding vulnerable adults, requiring them to be accompanied by a caregiver at all times.

YOU SHOULD ALSO BE AWARE OF ANY GUIDANCE OR LAWS IN YOUR COUNTRY AROUND SAFEGUARDING FOR VULNERABLE PEOPLE. A MINIMUM AGE REQUIREMENT MAY BE NEEDED TO FORM A GROUP.

LEARN AND ADAPT

For more established groups, some common experiences were:

- Some may join the group initially but decide it’s not for them in the longer term.
- Sometimes participants can become distracted during the meeting.
- Some people might wish to use the time to make friends rather than talk about issues.
- With time, you can build capacity by asking a group member to lead a session and having them encourage others in the room to participate.
- If your group is small and virtual, you may consider inviting people from different cities, states or countries to join. This is dependant on time zones and speaking the same language.

Our experts also discussed the option of including people who have other special needs, not PWS, in these meetings. The consensus was that the first step should always be to start with the people with PWS, because you need to experiment and develop a programme that works for them. Then as a next step it may also be possible to include those with other special needs.

WHEN & WHERE? DECIDING YOUR FORMAT, DAY AND TIME

Online or in-person?
There are benefits to both kinds of meeting.

ONLINE MEETINGS

- Cost effective
- Allows people to join from afar
- Often less time-consuming to attend
- Sometimes not needing to make eye contact can make it easier to speak freely

IN-PERSON MEETINGS

- Build stronger connections
- 1 to 1 discussion
- Allows more time to be taken
- Can provide a separate space for relaxation if meeting becomes overwhelming
- Body language is important

Considerations

ONLINE MEETINGS

Some members may need assistance with the technology.

Good access to internet is not available globally.

IN-PERSON MEETINGS

Consider if people need support with travel. Funding may be needed.

If food is going to be part of the meeting, it should be suitable for people with PWS. Share menus beforehand. Allow changes to suit specific diets.

WHEN & WHERE? DECIDING YOUR FORMAT, DAY AND TIME

Time and day

Members of your group will have established routines, activities, and weekly schedules which should be discussed in order to find a suitable time and day for your meeting. Our experts said that a weekend was preferable for many, however some will still have weekend activities planned which will conflict. The best you can do is find a time to meet which can suit the majority of people. When your meeting time is decided, make sure to announce it to the group as early as possible so that group members can plan for it. It is good practice to also send meeting reminders closer to the day.

It is preferable to stick to a set day and time once it is established, so that your group members with PWS can reliably include this in their forward planning and weekly routine.

Similarly, you may at first need to be flexible with the length of time for the meeting. One group initially had meetings of 90-minutes online, but feedback from group members was that it is hard to focus on an online meeting for 90-minutes, so this was changed to a 60-minute meeting.

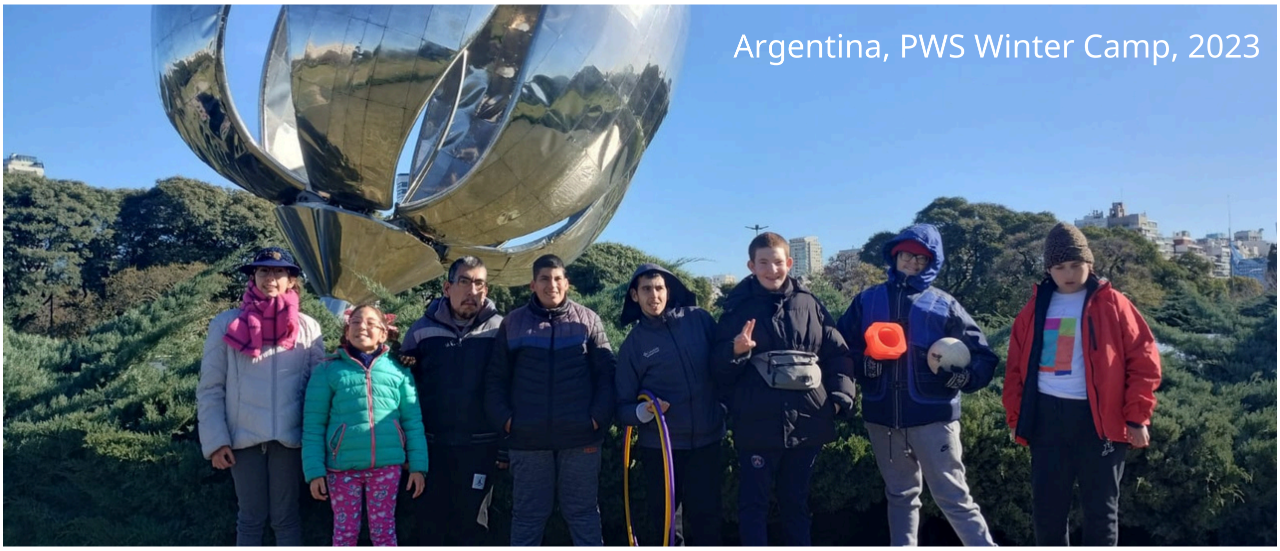
We've found that in-person meetings can be easier to focus in, with the groups we spoke to meeting for as long as 2-6 hours, punctuated by regular breaks.

WHAT? MEETING TOPICS

It is important that that the topics discussed at your meetings come from the meeting participants themselves. There are many subjects we know are important to people with PWS.
These include:

- Mental health/ Mental illness/ Mental wellbeing;
- Friendships, relationships and sexuality;
- Food security;
- Education and employment;
- Starting your own business;
- Importance of exercise and fitness;
- Mentoring;
- Stopping bullying;
- Travelling independently;
- Helping others to understand more about PWS.

As you would expect, there are many different individual opinions on things. Asking any one individual about a topic will elicit a different response so consensus is difficult. It is important to create a safe space where everyone can have their own personal views heard.



Argentina, PWS Winter Camp, 2023

AGENDA

People with PWS and their caregivers tell us that having an agenda with timings and set topics was appreciated, as it helps to plan and manage expectations for the meeting.

Agendas included:

- Introductions;
- Welcome to new people;
- Presentations by people with PWS on a topic of their choosing, prepared with support of a caregiver;
- Specific questions for the group to discuss together;
- Time for peer-to peer advice;
- Open topic to be suggested by the group;
- Discussion on next meeting's topics;
- Details of the time and date of the next meeting.

If your face-to-face meeting runs for a whole day or even several days, try to build in some social activities, eg. Walks, outings to the Zoo, etc. Encourage the group to provide social suggestions prior to the day.

HOW? TIPS FOR SUPPORTING PARTICIPATION

Start small

As bodies supporting people with PWS, we can be eager to ask for advice on strategy, organisational priorities, and advocacy right away. Bear in mind that some of these concepts are more abstract for a person not familiar with your work. That is why we start small, focussed on the things that matter to people with PWS. Our experience is that those who continue to meet with PWS groups learn more about the supporting organisation, and the kinds of work they do to support people with PWS, and how they can be involved.

Visual aids and PowerPoint presentations

Weaving PowerPoint slides into online or in-person meetings can improve focus and concentration of participants. One group invites individuals to lead the group discussion for the next meeting on a topic of their choosing. They are then supported, where necessary, to put together the slides during a 1:1 pre-meeting Zoom call.

Hints:

- Try to weave the ideas and language of the individual into their presentation by prompting them to consider aspects of the topic. This will assist them in formulating and practicing their live (online) presentation.
- Encourage them to invite discussion during their presentation to retain the focus of the audience.

With their permission, record the session and edit into a short film clip to enable sharing with a wider audience after the meeting. For example, record and edit the video from a Zoom call.

Show-and-tell

One group found that showing products that they had made in their own business was a good way to communicate their skills and encourage conversation. Recording these presentations can also demonstrate to a wider audience what types of 'meaningful purpose' might be possible for them. One group has enabled both online and in-person involvement of pets which has led to much discussion and individual presentations.

Time to think

It's always important to give individuals time and space to think and formulate their response. In one of the groups we heard from, the agenda is always shared in advance, and one woman likes to send her comments ahead of time. This is a great example of more creative ways of making sure everyone can participate.

Sometimes it can be helpful if a caregiver can help a person with PWS verbalise. Sharing comments ahead of time also helps the moderator to be able to prompt a more reluctant speaker to discuss points which are important to them.

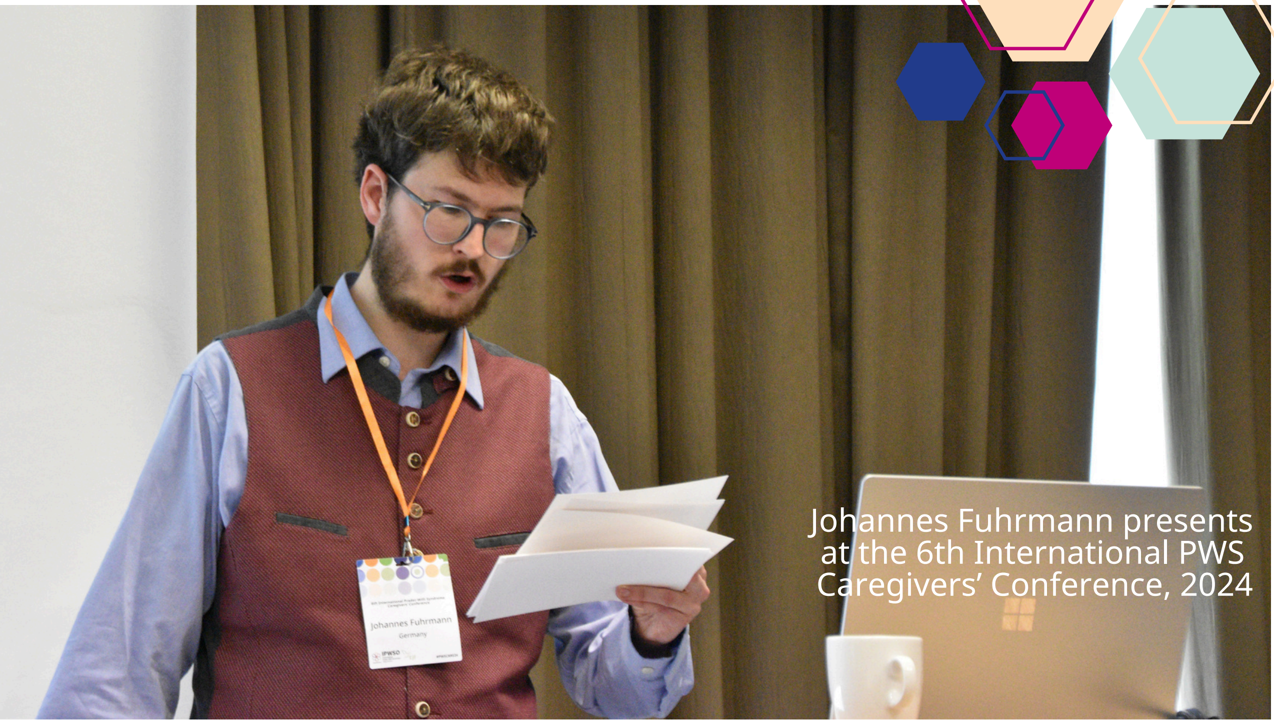
Example resources

We've gathered examples of resources for meetings with people with PWS on our website: Agendas, Anonymised meeting minutes, Example questions...and more!

Please visit this link to view them, and if you have resources from your own group meetings that you would like to share, please send them to office@ipwso.org.

Conclusion

People with PWS are capable of amazing contributions, given the right forum and the time to communicate. We're hopeful our guidance might help support your group to empower all people with PWS to participate and represent their local PWS community.



Johannes Fuhrmann presents at the 6th International PWS Caregivers' Conference, 2024

This is only the start of the journey for PWS groups; We are at the beginning of finding out how people with PWS want to represent themselves. Each PWS group will be different, tailored to the needs of the individuals in it.

In the coming years we hope to hear from more and more people starting their own PWS meetings around the world. We welcome any feedback or updates as your group develops, and look forward to hearing from and sharing experience from more and more forums for people with PWS to have peer-to-peer support and to have their voices heard.

Get in touch

If at any point you'd like to discuss your plans for meetings with people with PWS, or to ask advice, our People with PWS Committee are happy to support you. Email office@ipwso.org with your request and we'll be happy to put you in touch with the committee.

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Salisbury House, Station Road, Cambridge CB1 2LA, UK

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Pictured: Hungarian Prader-Willi Association Summer Camp, 2023