

**United in Hope:
International PWS
Conference
25 June 2025**

Shelly Cordner
Project Manager,
IPWSO, UK

Lynsey Moorehouse,
RNID, BNS,
Regional Operations
Manager PWS.
Resilience Healthcare,
Ireland



LathamCenters
Brighter futures since 1970

A place for professional PWS caregivers worldwide
to share practice-driven knowledge, information
and support.

Caregivers' Forum



About IPWSO

- Free diagnosis
 - Information and advice
 - Online meetings
 - Small grants
 - International advocacy
 - Research
 - Educational outreach
-
- CSAB
 - Famcare
 - PPCB

IPWSO was established in 1991. Since then, we have supported and connected national PWS associations, as well as people with PWS, their families and the professionals who work with them.

Forty-seven national PWS associations make up our current membership and we support individuals in over seventy other countries. While we are proud of our heritage and recognise that some people with PWS now achieve far better outcomes than were believed possible in the past, we are acutely aware that people with PWS and their families continue to face serious challenges, particularly in countries where knowledge is limited and treatments, services and support are difficult to access.



Caregiver Delegates

Caregiver Delegates are the point of contact that IPWSO's Professional Provider Caregiver Board (PPCB) uses to distribute information about residential support. Caregiver Delegates are appointed by their country's PWS Association.

At present, IPWSO has 12 appointed Caregiver Delegates, in Australia, Austria, Denmark, Ireland, Japan, the Netherlands, New Zealand, Spain, Sweden, Switzerland, UK, and USA.



The Caregivers' Forum

IPWSO supports this caregiver community by facilitating:

- 3 Caregivers' Forum meetings annually
- 3 Forum newsletters following meetings
- A webpage for the Forum which includes latest news and shared resources
- Ad-hoc support for networking in your own country.



Your Forum

The Forum is by PWS Caregivers,
for PWS Caregivers.

We want you to:

- Tell us about residential care in your country
- Share your experiences
- Contribute articles/blogs
- Useful documents
- Presentations
- Videos
- Advice
- Opinions!

scordner@ipwso.org





Previous Meetings

**Introductory Meeting
26 September 2024**

**The Experience of Grief for Residents and Staff in a PWS
Residential Setting
23 January 2025**

**Embracing Cultural Diversity in PWS Residential Care
22 May 2025**

[www.ipwso.org/news-
events/caregivers-
forum/caregivers-forum-
newsletters/](http://www.ipwso.org/news-events/caregivers-forum/caregivers-forum-newsletters/)



Challenges

Language barriers

Time zones

Funding

Busy caregivers

New voices



Mini-Forum

Live!

Supporting individuals with PWS in care settings that use less restrictive approaches.





Types of Restrictive Approaches

Environmental Controls

Routine Based Approaches

Behavioural Contracts

Physical Interventions



Alternatives to PWS Specific Environment

Structured Routines and Predictability

Positive Behaviour Support

Education and Visual Supports

Environmental Design (Smart Restriction)

Shared Decision Making

Therapeutic Interventions

Promote Healthy Lifestyle Habits



Alternatives to PWS Specific Environment cont.

Staff Training and Culture Shift

Use of Assistive Technology

Questions?
Email IPWSO Project Manager, Shelly Cordner
scordner@ipwso.org



www.ipwso.org/news-events/caregivers-forum/

