#### 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





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

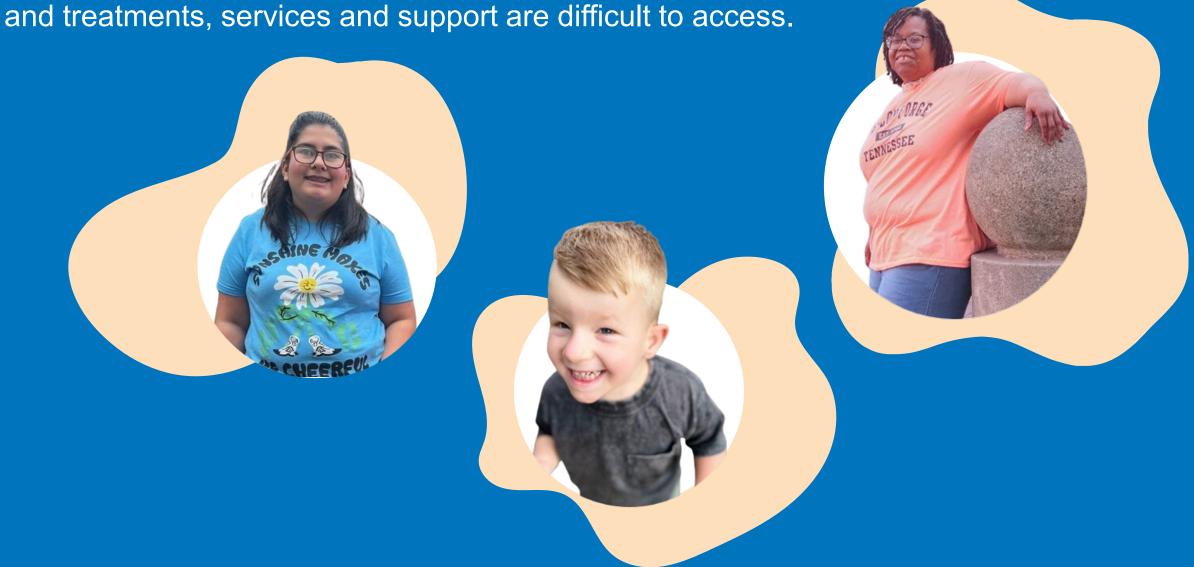




- Free diagnosis
- Information and advice
- Online meetings
- Small grants
- International advocacy
- Research
- Educational outreach
- CSAB
- Famcare
- PPCB

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



#### **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.

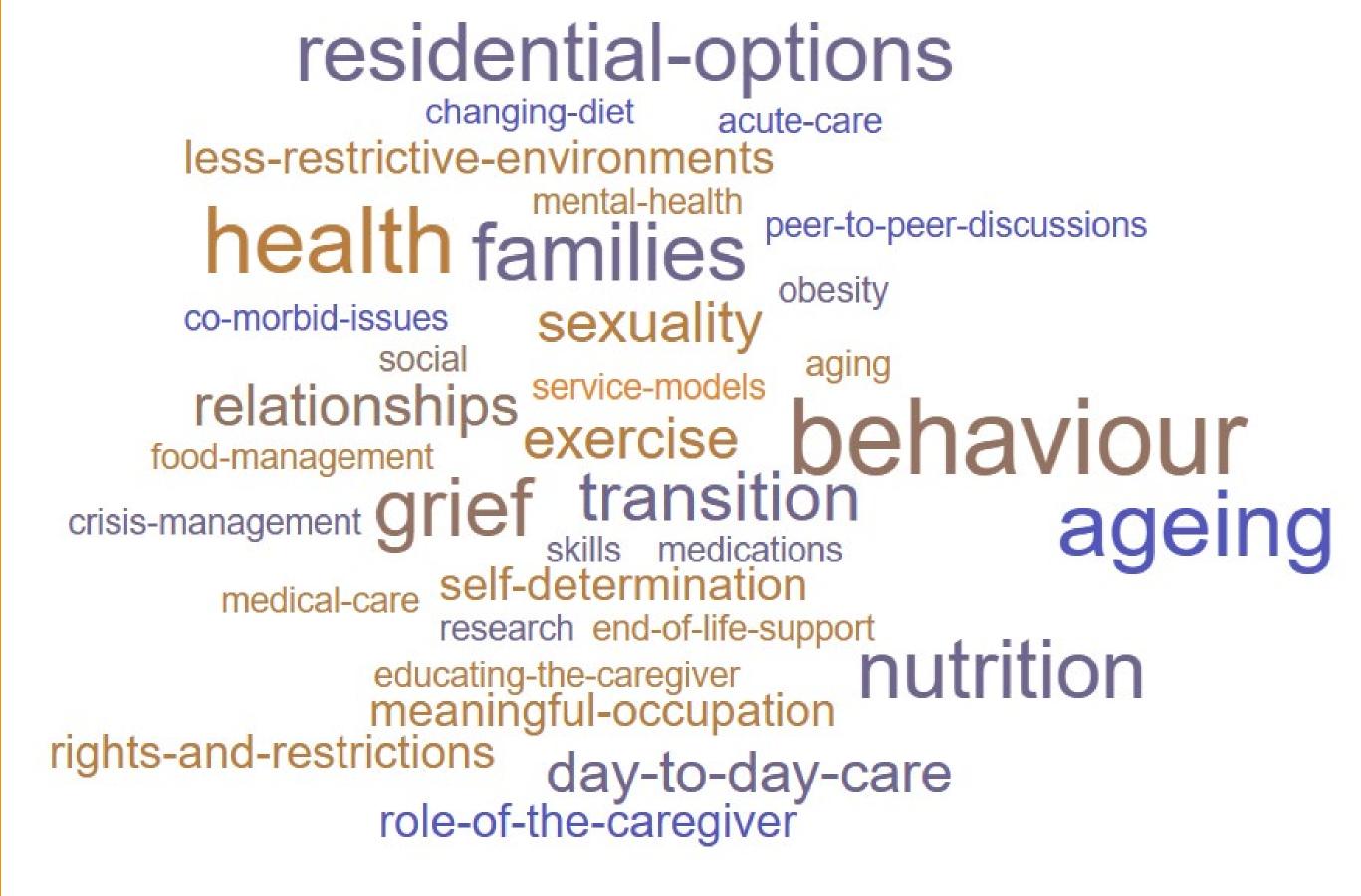


#### **Your Forum**

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!





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/newsevents/caregiversforum/caregivers-forumnewsletters/



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/

