

## Supporting People with PWS with very Challenging Behavior

Presented by **Patrice Carroll, Brittini Kliment, and Tony Holland**, this session explored the complexities of caring for individuals with Prader-Willi Syndrome (PWS), particularly those who fall outside the typical range of behaviors and needs—so-called *outliers*.

Key themes included:

- **Individualised Support:** People with PWS exist on a broad spectrum—varying in medical needs, food-seeking behaviors, and behavioral challenges. A one-size-fits-all approach is ineffective. Success depends on tailoring support to each person.
- **Scenario-Based Learning:** Attendees explored two case studies, one “high functioning,” the other “low functioning.” The takeaway: **staffing quality and staff-individual fit are crucial** to effective care.
- **Neuroscience Insights:** Tony Holland explained that people with PWS have structural differences in the **hypothalamus**, impacting hunger and behavior regulation. The reward pathways are heightened for food, while satiety cues are diminished, explaining persistent hunger.
- **Clarifying Anxiousness vs. Anxiety:** PWS is *not* an anxiety disorder, though many individuals experience *anxiousness* as part of their condition. Understanding this distinction is key to providing appropriate support.

The presentation encouraged caregivers and professionals to rethink their approach, grounding care in both **scientific understanding** and **person-centered strategies**.