

Caregivers' Forum

Meeting Notes | Thursday 24 September 2026, 1pm UK time

Meeting 07.

Attended

From IPWSO: Shelly Cordner (UK), Tony Holland (UK), Amrat Khorana (UK), Nora McNairney (UK)

From IPWSO's PPC Board: Lynn Garrick (USA), Neil Gumley (Australia), Lynsey Moorehouse (Ireland)

Caregiver Delegates: Bastian Bühler (Switzerland), Kim Herivel (Australia)

Other Forum Members attending the meeting represented Australia, Austria, Colombia, Denmark, Ireland, Italy, Japan, Nigeria, Sweden, Switzerland, UK, USA

36 people in total attended.

Please note in accordance with [IPWSO's Privacy Policy](#) we do not release the Zoom recording of the meeting, or list the names of general Forum Members without their express permission. PPCB and Caregiver Delegates have given advance permission to have their names listed in the Forum.

Members should contact Shelly Cordner scordner@ipwso.org in the first instance if they wish to connect with specific Forum Members over email.

Agenda

1pm: Welcome to the Forum

Neil gave a brief welcome and introduced Susanne and Lynn. The topic was **Medical and physical health needs of residents with PWS**. When registering to attend, participants were invited to select the physical health topic they most wanted discussed and to submit questions in advance. These responses helped guide the presentation and focus the meeting on the issues that mattered most to caregivers.

1:05pm: Dr Susanne Blichfeldt, Denmark, Lynn Garrick, USA

[A PDF of the slides can be downloaded here.](#)

Overview:

- Weight, BMI and body composition
- Nutrition and calorie requirements
- Physical activity and exercise
- Hormone deficiencies and treatment
- Medications and potential side effects
- Physical health monitoring
- Recommended health checks and blood tests
- When additional specialist input may be needed

1:15pm: Open Forum Discussion

These notes are a summary of the discussion evidenced in the saved meeting chat and are not a verbatim record. Several questions were answered verbally during the meeting but those answers were not captured due to a recording error and have therefore not been reconstructed.

Chewing, digestion and eating pace

A Forum Member asked for more information about chewing function and a low-fibre diet. Lynn commented that vegetables can be easier to digest when steamed or cooked.

There was also a question about whether feeding therapy can help people slow down, chew and eat more safely. A further question was raised about preventing regurgitation.

From the chat: A dietitian shared a strategy previously used in practice: encouraging people to put down their utensils between each mouthful of food.

Further information: People with PWS can experience swallowing difficulties related to factors including low muscle tone and delayed swallowing. PWSA USA recommends calm, unhurried mealtimes, small bites and slow sips, allowing sufficient time to chew, sitting upright and keeping mealtimes free from distractions. Where there are concerns about chewing or swallowing, assessment by an appropriately qualified professional, such as a speech and language therapist, may be needed.

[PWSA USA: Swallowing in Prader-Willi Syndrome – A Family-Friendly Guide \(PDF\)](#)

DEXA scans, osteoporosis and bone health

Questions included how frequently DEXA scans are currently recommended and, where a DEXA scan is not available, whether there are warning signs for osteoporosis or alternative tests.

From the chat: Regular physical activity, particularly weight-bearing exercise, helps slow the development of osteoporosis.

There was a question from Colombia, about annual zoledronic acid treatment for osteoporosis. Resource shared: [PWSA | USA: Osteoporosis, Calcium & Vitamin D](#)

A further question asked whether bone turnover marker testing in blood or urine is recommended for monitoring bone health in PWS. No answer was captured in the chat.

Further information: A 2023 study providing clinical recommendations for bone health in adults with PWS recommends DXA screening every five years where the previous DXA showed normal bone mineral density, and every two years where osteopenia or osteoporosis is present. Where possible, vertebral fracture assessment should also be included. The authors note that fractures can sometimes be difficult to recognise in people with PWS because of differences in pain perception. [Read the clinical recommendations](#).

PWSA USA also provides guidance on the evaluation and management of osteoporosis in PWS, including DXA scanning, relevant blood tests, exercise, calcium and vitamin D, hormone status and treatment. [PWSA USA: Osteoporosis Evaluation and Therapy in PWS](#)

Growth hormone and physical health

A Forum Member noted that in Australia BMI needs to be below 40 kg/m² before a person is considered for growth hormone treatment. She also commented that spinal problems are sometimes seen in people with PWS over 60 who did not receive growth hormone.

A Forum Member asked whether the group had seen cases where growth hormone was restarted after being stopped and what happened following restart.

Further information: Research in adults with PWS has found that growth hormone treatment can improve body composition, increasing lean body mass and reducing fat mass. Some studies have also reported deterioration in body composition following withdrawal of treatment. Evidence specifically examining the effects of restarting growth hormone after a period without treatment remains limited. Growth hormone treatment in adults should be managed and monitored by an appropriate specialist team. [Read a systematic review of growth hormone treatment in adults with PWS.](#)

Body temperature, urination and behavioural change

A Forum Member asked whether difficulty regulating body temperature and/or difficulty urinating could be related to behavioural changes in people with PWS.

Lynn responded that behavioural issues can often be the first clue that there is a medical issue that needs to be addressed. When the member added that the person had been feeling hot, irritable and having urination problems, Lynn raised dehydration as something to consider and noted that the person may simply have a lower threshold for tolerating heat.

In response to a question about normal body temperature, Bastian explained that temperature varies between people with PWS. At his residential group in Switzerland, temperature is measured for five consecutive days each year to establish an individual baseline.

Further information: Difficulty regulating body temperature is recognised in PWS and may include unusually high or low temperatures or difficulty responding normally to environmental heat or cold. Because temperature responses can be atypical, caregivers should be alert to changes from the person's usual state rather than relying solely on a standard temperature range.

PWS-specific medical guidance also highlights altered pain perception and temperature abnormalities as important considerations when assessing illness. A change in behaviour may therefore warrant consideration of an underlying medical problem, particularly where it occurs alongside new physical symptoms. [IPWSO Medical Alerts Booklet.](#)

[Foundation for Prader-Willi Research: Temperature Control and PWS.](#) A very accessible 2026 overview explaining what is known about temperature dysregulation in PWS. It notes that people may become unusually hot, have difficulty cooling down, experience unusually low temperatures, or have temperature changes that do not correspond to their environment.

[PWSA USA: Hypothermia and Prader-Willi Syndrome.](#) This gives additional background about reports and research concerning abnormal temperature regulation in PWS.

Peptides and fat mass

A question was raised about whether consuming peptides can help reduce fat mass.

Further information: A number of peptide- or hormone-based treatments have been investigated in PWS, including oxytocin and treatments acting on GLP-1 or ghrelin pathways. However, these are specific medical treatments rather than dietary peptide supplements, and there is currently no general recommendation that consuming peptides reduces fat mass in people with PWS.

[IPWSO: Is there a role for GLP-1 Receptor Agonists in Prader-Willi Syndrome?](#)

Dementia-like symptoms and low sodium

A Forum Member asked whether people with PWS are at increased risk of developing dementia and whether there are studies on this topic.

From the chat: Another Member shared an experience of low sodium levels presenting with symptoms similar to dementia. Lynn agreed this was an important point and noted that some psychiatric medications can contribute to low sodium, as can excessive fluid intake.

Further information: Dementia has been reported in adults with PWS, but evidence about its prevalence and risk factors remains limited and further research is needed. Some research has also identified signs of accelerated biological and brain ageing in PWS, although this does not mean that dementia is inevitable. [Read more about ageing research in PWS.](#) [\[pwsausa.org\]](#)

Low blood sodium (hyponatraemia) is also a recognised medical issue in PWS and can cause neurological symptoms, including confusion when severe. A large international study identified psychotropic medication and excessive fluid intake among the potential contributing factors and recommended monitoring serum sodium as part of routine PWS follow-up. [Read the study on hyponatraemia in PWS.](#)

Medical alerts and respiratory guidance

During the discussion, the following resources were shared with participants:

IPWSO Medical Alerts: <https://ipwso.org/information-for-medical-professionals/medical-alerts-booklet/>

PWSAI medical information/alerts: <https://pwsai.ie/multi-media-2/medical-overview/>

IPWSO guidance on respiratory issues: https://ipwso.org/wp-content/uploads/2026/07/2026_IPSWO_Chest_infection_draft_3_2_7_2026.pdf

Exercise, muscle tone and ankle weights

The importance of exercise was reinforced during the meeting, with Lynn commenting that “exercise is medicine.”

A Forum Member asked whether using ankle weights while walking might help people with PWS gain muscle tone or whether this could be counterproductive. Lynn said she would be more concerned about balance and falls.

Further information: Regular exercise is particularly important for people with PWS because reduced muscle tone and muscle mass are common. Exercise can help maintain muscle, increase energy expenditure and support bone and cardiovascular health. Research has also identified poorer balance in adults with PWS, supporting the importance of exercises that

develop strength and balance. There is limited evidence specifically on the use of ankle weights while walking in PWS, so additional resistance should be tailored to the individual and introduced with appropriate professional guidance where balance or mobility is a concern. [IPWSO: Exercise for people with PWS](#).

Oedema and lymphoedema

Towards the end of the meeting, Lynn Garrick noted that lymphoedema and general oedema are different conditions.

Further information: Oedema is a general term for swelling caused by excess fluid in the tissues, whereas lymphoedema occurs when the lymphatic drainage system is not working effectively. Persistent or unexplained swelling should be medically assessed to establish the underlying cause and appropriate management.

Future topics and upcoming meetings

2027 Caregivers' Forum meetings: Dates and topics for the 2027 meetings have not yet been set. These will be announced towards the end of 2026.

Family Meetings: <https://ipwso.org/news-events/family-meetings/>

Summit Meetings: <https://ipwso.org/news-events/summit-meetings/>

Caregivers' Conference 2027: <https://ipwso.org/news-events/caregivers-conference-2027/>

2:25pm: Close and thank you

Participants thanked the speakers and group for an informative discussion and for sharing expertise and experiences. The meeting closed at approximately 2:25pm UK time.

For detail on upcoming IPWSO events visit: <https://ipwso.org/news-events/>