

October 2023 Newsletter

Association News

Our second weekend for adults living with PWS is happening soon! The programme is a mix of leadership and social activities, with a record number of 22 adults living with PWS registered to attend. One of the leadership activities the group will be working on involves learning to work together as an advisory group.



LEADERSHIP AND SOCIAL WEEKEND for Adults Living with PWS
3RD—5TH NOVEMBER 2023, SURREY HOTEL, AUCKLAND

FRIDAY: Check in at the hotel anytime from 2pm. You may wish to meet up, hang out at the hotel or go sightseeing.
Programme Start:
6pm Dinner (Hotel Restaurant / Sussex Room)
From 7pm (Cornwall Room): Welcome & Introductions
Icebreaker Activities
Games

SATURDAY:
7.30—8.30 Breakfast (Hotel Restaurant / Sussex Room)
From 9.00am (Cornwall Room): Learning from Experiences
Morning Tea
Role-plays
12.30—1.30 Lunch (Hotel Restaurant / Sussex Room)
1.30—2.00 Free time
From 2pm: Out and About Scavenger Hunt (meet in Cornwall Room)
Swim and Relax at the Hotel Indoor Pool
5.00—6.00 Dinner (Hotel Restaurant / Sussex Room)
From 6pm (Cornwall Room): Lip-Sync Contest - Rehearsals and Show-time!
Games

SUNDAY:
7.30—8.30 Breakfast (Hotel Restaurant / Sussex Room)
Check out of rooms / store bags at reception.
From 9.00am (Cornwall Room): ALPWS Advisory Panel
Morning Tea
11.15 ALPWS Advisory Panel Go Live!
11.30/12.00 Programme ends

The group will work on how best to answer some important questions gathered from the community, and this session will be recorded by our videographer.

We will then try 'going live' via Zoom so the group can answer further questions. This will take place **Sunday @11.00am**.

The zoom link and further details will follow later in the week.


The advisory group might be able to answer questions from parents, siblings, teachers, or support service providers.

Can we please also gently remind those attending about returning the consent and release forms for the videography.

We also have a new resource available - a medical alerts poster. This has been produced with the intention that it is displayed in residential support services in a prominent place, where it will be seen by new or relief staff who may not have received PWS training.

With frequent staffing changes in the disability support sector, it is essential that any new staff are made aware of the health risks associated with PWS.

Posters can be found on our website on the [Medical Alerts](#) page and from the [Publications and Resources page](#). You can also [contact us](#) to post some to you.



PWS PRADER-WILLI SYNDROME ASSOCIATION NEW ZEALAND

Prader-Willi Syndrome (PWS) Medical Alerts

PWS is a complex neurodevelopmental disorder resulting from an abnormality at chromosome 15. It causes hypothalamic dysfunction and features such as hypotonia (low muscle tone), hyperphagia, altered metabolism, hypogonadism, learning disabilities, anxiety and impaired self-regulation.

Vomiting / Abdominal Distention or Pain
Urgently evaluate abdominal bloating, distention, discomfort or pain, appetite loss, and/or vomiting (less common in PWS), extra flatus or odorous belching. Life-threatening inflammation, necrosis or rupture can occur, especially after suspected binge eating. Slow gastric motility, constipation or obstruction are common. Signs of infection may be absent (fever or localised pain). Vomiting may be weak due to hypotonia, which creates a choking or aspiration risk and the recovery position should be adopted. A lack of vomiting is also of concern during gastric illness or if poisons have been consumed.

Hypertrophagia (Excessive Eating)
Dangerous volumes of food may have been consumed, or unhygienic, frozen, raw foods, inedible items or poisons.
Plus, excessive fluid intake may cause electrolyte imbalances and cause water intoxication (potentially fatal low sodium).

High Pain Threshold
Some people with PWS have decreased sensitivity to pain which can mask injuries or illness. Pain may not be felt until severe. Note any subtle changes in behaviour. A person may also be unable to localise or describe their pain well.

Body Temperature Irregularity
Normal body temp may be altered. Temperature instability may cause a person to not present with a fever when seriously ill, or temperature may be higher than expected (or idiopathic). Slight changes in temperature should be evaluated. Hyper and hypothermia can occur (impaired peripheral and central thermoregulation.)

Respiratory Concerns
Possible complications from hypotonia and potential apnoeas (CSA/OSA). More frequent problems with young age, narrow airway, or morbid obesity. Monitor when unwell. Silent aspiration and hypoventilation are common. Altered ventilatory control responses. PE risk.

Swallowing and Choking Risk
Dysphagia (swallow dysfunction) is typical. Choking risk due to voracious eating habits, oral/motor coordination, poor gag reflex and hypotonia. Reduced and thick saliva flow, so maintain hydration. Supervise. Know first aid.

Skin Sores & Infection
Skin picking is common, sometimes severe. Monitor open sores for infection and cellulitis.

Diabetes Mellitus
Increased risk with some meds and after puberty (avg 20yrs). Observe for signs of high blood sugar.

Mental Health Problems
High prevalence, particularly in adolescence and early adulthood, often with rapid onset. Can include acute psychosis. Unusual reactions to standard doses of medications.

PWS Training

Cindy has been very busy lately running PWS training workshops around the country. We would like to take this opportunity to remind you of the training services we offer, either in-person, or via Zoom. Full details and a booking form can be found on the [training page](#) of our website.

Halloween - tips and ideas



If you are planning to celebrate Halloween this year, our Halloween blog post contains some suggestions that can help with making Halloween a safe and healthy celebration for individuals living with PWS.

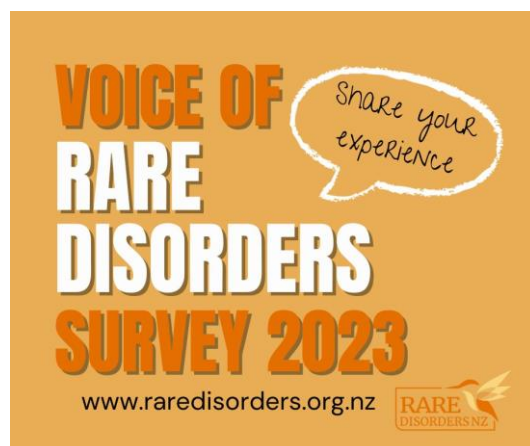
Click here for [tips & ideas >](#)

Rare Disorders NZ Survey - closes Oct 31st

Last chance to complete the RDNZ biennial survey! This survey is important because no comprehensive data is collected on rare disorders in New Zealand. Let's have the voice of the NZ PWS community included! The survey is open to anyone living with a rare disorder in Aotearoa New Zealand, as well as their carers and whānau. [Access the survey here >](#)

[RDNZ](#) collect essential data on what it means to live with a rare disorder, and the barriers people continue to face within the health and social systems to access the care they need.

This data is used to inform and educate stakeholders and policy makers, and to continue to push for meaningful change, such as the development of a health strategy for rare disorders and the establishment of centres of expertise.



Private age-based Facebook groups

Have you signed up to the new age-based Facebook groups launched in July?

We are still maintaining our all-ages group which is useful for general or local discussion.

0-5 years - [NZ PWS Whānau Support: 0-5 years](#)

6-12 years - [NZ PWS Whānau Support: 6-12 years](#)

13+ years - [NZ PWS Whānau Support: 13+ years](#)

All ages - [NZ Prader-Willi Support Community \(Parents\)](#)

And we also have our group specifically for adults diagnosed with PWS:

[My PWS Online Network \(For New Zealanders living with PWS\)](#)



IPWSO Family Meetings - Siblings

HAVING A BROTHER OR SISTER WITH PWS

Saturday, 25 November, 2023
9am and 5pm London, UK time

Join us for the next IPWSO Family Meeting when we'll focus on the siblings of people with PWS, the unique challenges they face, the rewards, and how best to support siblings within the family.

For more information and to register:
www.ipwso.org/news-events/family-meetings



IPWSO's next family meeting is focusing on the siblings of people with PWS and is directed at parents and families.

Date and times in Aotearoa New Zealand:

Sat 25th November 10pm

Sun 26th November 6am

Registration is required. Click here for more details and [registration >](#)

We Care Campaign - Carers Alliance Petition

The Carer's Alliance are calling for the Government to establish a Minister or Commissioner for family carers, and to develop protective legislation, programmes, and services to sustain carers physically, mentally, and financially. This is a large campaign with almost 5000 petition signatures already. It closes on Jan 31st.

Click here to read about the [We Care campaign](#).

Click here for information and resources from [Carers NZ](#).

Click here to sign the [petition to Parliament](#).

Research Update - DCCR

In September, [Solenio Therapeutics](#) announced exciting results from their withdrawal phase of study C602 for PWS with DCCR (Diazoxide Choline), and they hope to submit a New Drug Application (NDA) to the USA's Food and Drug Administration next year.

DCCR is thought to [affect leptin pathways](#) and a key result was that hyperphagia-related behaviours improved significantly with no new safety concerns.

You can read more about the history of the [DCCR studies here >](#)

Notices / Events

Dates for your Diary

ALPWS Leadership & Social Weekend - Fri 3rd - Sun 5th November

ALPWS Advisory Panel via Zoom - Sunday 5th November 11.15am

IPWSO Meeting for Siblings - 25th and 26th November

Next Asia Pacific PWS Conference, Sydney - 30th-31st August, 2024

Next IPWSO Conference - USA, 2025!