

OCTOBER 2025 NEWSLETTER

PWSA(NZ) Committee News

We are pleased to share with you our [Strategic Plan 2025-2030](#) and this is available to view by clicking on the link, or via our website 'Your Association' page. We have set ourselves several ambitious projects which various subcommittees will be working on. If you see a particular project that you would be keen to contribute to, please get in touch.

New Resource Available for Hospital Admission



This is a similar idea to the Health Passport which records patient details, but our folded A3 resource is PWS-specific and also includes a page of information about PWS to aid clinical evaluation. It is brief enough to be user-friendly in an emergency and is printed on bright orange paper so it is also easy to grab. [Order](#) from our website or [view / download](#) from our resources page or Medical Alerts / A&E Resources page.

ALPWS Leadership Group Update

The topic of the last ALPWS Leadership Group meeting in September was job opportunities. Olivia told us about her own business selling plants that she grows from seed and Margaret told us about her volunteering work at Wellington Zoo. Margaret has kindly written something about her job to share in this newsletter:

Becoming a Vollie.

I started off looking for somewhere to volunteer that was also inclusive to all types of people.

A little on me, I value conversations with people and being part of a busy team. A big passion I have always had in my life is animals.

I volunteer in the nutrition centre. For the work, you need to be able to do basic reading and read scales and know how they work.

If this sounds like you then look online to find the nearest zoo to you that offers volunteering.

It also stands out on your CV as a different volunteer job if looking for employment.

Best of luck Margaret

The next ALPWS meeting is **Monday 10th November @ 7pm**. Link and details to come.

Advocacy Updates

Rare Disorders New Zealand have asked that we remind you about their biennial survey as responses from the PWS community are still quite low. Please help the voice of the PWS community be heard!

The survey can be completed by anyone who lives with a rare disorder or cares for someone with living with a rare disorder. We know your time is valuable – but so are your responses!
Survey closes Oct 31.
Please [take the survey today!](#)



Anonymised data from surveys is used:

- ✓ To inform health professionals on how best to support patients living with rare disorders.
- ✓ When presenting to Ministers and officials about the impacts of living with rare disorders.
- ✓ In submissions on proposed policy changes that could impact the rare disorder community.
- ✓ To advocate for improved systems and services for the rare disorder community.
- ✓ When educating the public and raising awareness about rare disorders in Aotearoa.

In September we submitted a response to the [draft New Zealand Disability Strategy 2026-2030](#). The draft strategy focused on 5 priority outcome areas: Education, Employment, Health, Housing, and Justice. We felt key actions were missing which are listed below.

- Holistic, multidisciplinary, collaborative approaches.
- Diagnosis-based care and support needs mapped out.
- Availability of centralised expertise.
- Improving mental health provision for disabled people.
- Specific targets and actions to reduce the early mortality of people living with intellectual disabilities.
- More disability specific residential support options (for PWS).
- More flexibility in where people with ID and full-time support needs can live that addresses current funding issues.
- Preventing discrimination and protecting the rights of disabled learners in the education system.
- Access to learning support funding for ALL pupils with ID or learning disabilities by ensuring funding increase meets need.
- Widening and extending transition from school support.
- Recognising the diversity of disabled employees, looking beyond traditional views of employment to include and promote disability specific opportunities such as social enterprise schemes.
- Addressing financial barriers to employment.
- Recognition of rare disorders as a significant disability group who often experience complex unmet needs.
- Mandatory training if supporting people with complex health needs.

Of particular concern, the strategy lacked specific actions to address the high early mortality rate of intellectually disabled New Zealanders; there was no focus on developing multidisciplinary healthcare approaches or holistic approaches overall, and there was no mention of improving mental health provision for disabled people.

The strategy also did not address the financial barriers to employment and choice in housing.

You can read our [submission here >](#)

PWS Clinical Trials

Unfortunately, we have some disappointing news about the ability of New Zealanders to participate in the phase 3 trial of ARD-101 in Australia. After much deliberation the teams decided there were risks in being able to manage any adverse events if they were to occur when a patient lives outside Australia, and the sites did not have experience of this.

However, we intend to maintain a positive relationship with Aardvark and look forward to them bringing ARD-101 to New Zealand once this trial is complete. We also continue to do what we can to bring other hyperphagia trials and treatments to New Zealand.

We would still urge you to consider attending the launch Q&A webinar for the Australian ARD-101 HERO trial to find out more about ARD-101 and to help convey the strength of interest in hyperphagia treatments in New Zealand - **Sat 18th Oct @ 11am NZ time.**

You can register here: praderwilli.supporterhub.net.au/events/hero-webinaresept2025



Pitolisant - TEMPO Study

There is still the opportunity to participate in the phase 3 trial of pitolisant with funded travel to Australia. Pitolisant is approved in the US and Europe for patients diagnosed with narcolepsy and is a potential treatment for EDS (Excessive Daytime Sleepiness) in PWS, which may also provide other behavioural benefits.

TEMPO is a randomised, double-blind, placebo-controlled trial with an open-label extension period. The treatment period will be 11 weeks (pitolisant or placebo), with eligible participants having the option to continue in the extension period. Study participation may take around 4-6 months overall with about 5 site visits.

PWS patients **must be 6 years of age or older** and experience EDS. The trial is mainly evaluating effect on EDS, but will also evaluate impacts on severity of irritability, disruptive behaviours, and hyperphagia. TEMPO trial: www.youtube.com/watch?v=do0FkvDg6eA

Adults

- Royal Prince Alfred Hospital, Sydney, Tegan Picone, tegan.picone@sydney.edu.au

Children (under 18)

- Sydney Children's Hospital, Silvia Hudakova: silvia.hudakova@health.nsw.gov.au and cc the Sydney Children's Hospital study centre: schn-schclinicaltrials@health.nsw.gov.au

- Qld Children's Hospital Brisbane, Megan Angliss, chq_pwsresearch@health.qld.gov.au

New PWS Resource Alert



PWS United Podcast - Nutrition Recommendations for PWS

Some fantastic, clear information about diet recommendations for PWS from the 2025 IPWSO conference by Michael Tan, MS, RD, LDN, CDCES, registered dietitian.

We recommend [downloading the slides >](#)
You can also listen to the [podcast >](#)

IPWSO Professional Caregivers' Forum Update

It was wonderful to see so many residential service providers from New Zealand attend the last forum meeting. The topic was **"How to establish a PWS residential home"** and some valuable discussions took place around some of the issues. You can read [summary notes and forum newsletters here >](#)

We think it would be fantastic if there was interest in a national forum for PWS service providers? Sharing experiences facilitates learning from others, developing best practice, and helps with overcoming challenges.

As you will see in our Strategic Plan, one of our goals is for more PWS specific residential support options to be established in New Zealand. PWS specific support can help manage hyperphagia, anxiety, and behaviours of concern, while providing safe, structured environments where individuals can thrive.

The next Forum meeting will be on January 22nd at 1pm UK, which is unfortunately at the unsociable hour of **2am on FRI 23rd JAN in NZ.** The topic is **"Ageing in PWS."** Anyone working in a paid role supporting people with PWS is welcome to join the forum, supported by the Professional Providers and Caregivers Board (PPCB) of IPWSO, an advisory board dedicated to sharing best practice, information, knowledge and techniques.

Click here to [join the forum >](#)

How to establish a PWS residential home



IPWSO are also keen to hear from members wishing to contribute to the forum in any way so that PWS Caregivers help shape the advice and information that comes out of the forum. Some of the ways you may be able to contribute are:

- writing to them about residential care in New Zealand
- contributing an article, blog, useful documents or videos

With any questions or contributions, contact Manager [Shelly Cordner](#).

MY-HQ global PWS Hyperphagia Study

WE WANT TO HEAR YOUR VOICE!

We want to find out how hyperphagia affects you and your family.

We are looking for children and adults (10-adult) with PWS who will tell us about how hunger affects their life. This will help others understand when and if hyperphagia treatments are working which is a main aspect of FDA push for patient voices in clinical trials.

The study is virtual and will take less than 20 minutes for parents and less than 20 minutes for their child with PWS in a ZOOM call with an interviewer. We will provide feedback about the study in 2025.

SCAN HERE!

Questions?
Please contact elizabeth.roof@vanderbilt.edu or 615-343-3330.
Or Scan the QR code if you are ready to be a part of the study.

Photo: emilypa / iStock

Prof Elizabeth Roof at Vanderbilt University is looking for children and adults with PWS (age 10+) to tell them how hunger affects their lives. MY-HQ is a virtual study that takes less than 20 minutes for the parent and less than 20 minutes for the person living with PWS.

The MY-HQ interview takes place over Zoom with a trained and supportive interviewer. It's casual, comfortable, and designed to be a positive experience for participants with PWS. Interviewers use simple, concrete language and helpful pictures.

If you are interested in participating, email: elizabeth.roof@vanderbilt.edu or you can scan the code in the MY-HQ flyer.

This is an exciting project because most studies and clinical trials measuring hyperphagia have relied solely on parent or caregiver reports. MY-HQ is being developed as a structured tool to capture the individual's own experience with hyperphagia - giving a vital new perspective. This is also important because regulatory bodies such as Medsafe and the FDA can require validated patient-reported outcomes before approving new treatments.

Changes to Flexible Funding

We are sure you will already be aware but here is a recap of the key changes to flexible funding announced last month:

- Flexible funding budgets will be linked to a personal plan.
- Reallocation of budgets will be based on June 23 - June 25 spending from April 1st.
- The purchasing guidelines will no longer be used from April 1st.
- Pre-approval will be required for purchases over a set value.

- NASCs will use standardised assessment processes.
- There will be a pause in reassessments Feb - Oct 2026. People who are new to disability support services will be assessed using the new system from Feb 1st.
- Reassessments including the development of personal plans begins from Oct 1st.

The intention is that you should be able to return to more choice and control in how you use your funding, but please let us know if you find that the changes do not work for you, or if your funding is reduced and unmanageable.

You can find out more about the changes via [Whaikaha's website >](#)

Dates for your Diary

PWRFA & Aardvark Webinar - Hero Trial - Sat 18th Oct @ 11am NZ time

Voice of Rare Disorders Survey closing - Fri 31st October

Next ALPWS Leadership Meeting - Mon 10th November @ 7pm

Next IPWSO Caregivers Forum - Fri 23rd January @ 2am

Copyright © 2025 Prader-Willi Syndrome Association NZ Inc.

Contact Us:

www.pws.org.nz | enquiries@pws.org.nz | 0800 4 PWS Help