

November 2024 Newsletter

Kia ora,

This will be our last newsletter for the year so we will take this opportunity to wish you early seasons greetings and send you our best wishes for a restful summer break!

Transition Symposium



We held our first transition focused event during October which we hope was beneficial to those who attended, but it was also a learning process for us as a team to work through all the issues whilst planning this event!

[Read more about this event here >](#)

We are very grateful to our invited speakers for giving up their time to present for us and to the [International Prader-Willi Syndrome Organisation \(IPWSO\)](#) and Friends of IPWSO(USA) for their assistance with funding.

Our next step is to compile some of the information shared at the event into useful transition packs for families and support agencies.

Family Support Camp 2025

A reminder that registration is open for our Family Support Camp, **Friday 21st - Sunday 23rd March** at MiCamp Taupō. Register **by January 31st**.

People of all ages with PWS are welcome to attend with their family or a support person and we have an exciting new programme being developed by the organising committee! If you are planning to book flights from the South Island, we urge you to book these as soon as possible before seats sell out and prices increase.

Click here for [further information >](#) Click here [to register >](#)

New Initiative - IPWSO Caregivers' Forum

Where PWS Support Staff can share Knowledge, Information and Support.

The Caregivers' Forum is an excellent initiative to connect residential support providers, both nationally and internationally. Support staff who have attended PWS events and conferences often say how beneficial it is to share experiences with staff from other organisations - we can all learn from each other, gaining insights and ideas. This forum is a virtual space for PWS caregivers to connect and collaborate, supported by the [Professional Providers and Caregivers Board](#) (PPCB) of IPWSO.



Would you like to join? The next meeting is **Friday January 24th at 8am (NZ time)**. There will be 3 meetings per year and this one is more ideal for our time zone. (Meetings are held at different times to suit time differences, so no expectation to join all meetings.)

- 3 Caregivers' Forum meetings annually
- 3 Forum newsletters following meetings (Click here for the [first newsletter](#))
- A Forum webpage which includes latest news and shared resources
- Ad-hoc support for networking in your own country

Click here for the [information booklet](#). Click here to [join the forum](#). After joining, you will receive invitations to meetings, newsletters and shared resources. Spread the word!

DCCR - for the treatment of hyperphagia in PWS



You are probably aware of the anticipation in the international PWS community around the pending FDA decision on [DCCR](#). A review decision was expected Dec 27th but this has now been set back 3 months whilst new information is evaluated.

If Soleno Therapeutics's new drug application to the FDA is successful, DCCR will be the first hyperphagia treatment approved for people with PWS. This is very exciting, but it is important to understand that DCCR will not work for everyone and that multiple hyperphagia treatments will be needed to treat the complexity of hyperphagia in PWS.

If DCCR is approved by the FDA, it will then be some time before it will be available in New Zealand, but we want to assure you that we are already working on what we can do to make this happen sooner. A rough timescale to consider is that Soleno Therapeutics would

apply to other regulatory authorities after the FDA and these are likely to be larger authorities, i.e. the EMA in Europe. Once Soleno (or licenced company) sponsors an application to Medsafe, our regulatory authority, the assessment process could take up to a maximum 200 days. Once approved, we can then apply to Pharmac for funding of DCCR.

Guanfacine News

If you have been following Dr Deepan Singh's [guanfacine trials](#), you will be aware of the positive benefits shown for aggression, agitation, and self-injurious behaviour (skin picking) in PWS. Guanfacine is a non-stimulant ADHD medication and Dr Singh argues that most people with PWS have ADHD symptoms that would meet the prescription criteria for guanfacine. It is available for the treatment of ADHD in many countries, but is not currently available in NZ, although some families have been able to have guanfacine prescribed under section 29 of the Medicines Act, with the medication being imported from Australia.

We have been ensuring that guanfacine is on Pharmac's radar, have been in discussions with suppliers, and have some good news that an application has just been submitted to Medsafe. Due to guanfacine already being approved by multiple authorities overseas and its good safety profile, we are hopeful that it may follow an abbreviated assessment route and Pharmac can then advance funding applications made to its clinical advice phase.

Rare Disorders Strategy - Action Needed



As mentioned in previous newsletters, we finally have a published [health strategy for rare disorders](#) - it didn't contain everything that was hoped for (patient registries / data collection, coding systems, centre of expertise), but it was an important first step and official recognition of the unique challenges and needs of those living with rare disorders.

However, the strategy is yet to be implemented and planning for this has now been placed on hold whilst Te Whatu Ora undergoes a reset. This is completely unacceptable when the rare disorder community have already waited so long and experienced poorer health outcomes as a result. Life-changing improvements to the health system are needed immediately - please sign and share RDNZ's petition demanding action:

rdnz.nationbuilder.com/petition

Conference Summary: APPWS2024



A conference summary report has been sent to inboxes. If you have not received or had chance to read the report, you can click here to [access](#) and [read the report](#).

PWRFA have sent a link for the day 1 video recordings of research presentations to all registered attendees. The day 2 video recordings should follow soon.

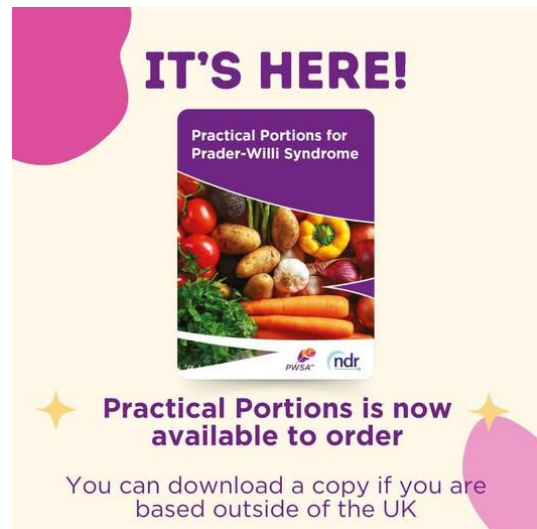
Did you know that APPWS2021 recordings are freely available? You can [view here](#).

New PWS Resource Alerts

Practical Portions for PWS

This is a useful new guide available from PWSA UK. Practical Portions was created by dietitians and nutritionists specifically for the PWS community, designed to make it easy to work out appropriate portions.

Freely available to download here:
www.pwsa.co.uk/practicalportions

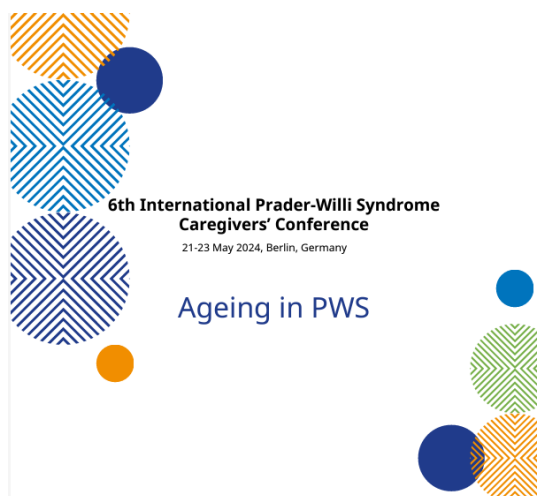


IPWSO PPCB Workshop Summaries

Workshop summaries from IPWSO's 6th Professional Providers and Caregivers Conference have been made available to help spark discussion on important topics amongst providers.

The documents summarise key points and takeaways, covering topics such as ageing, friendships / partnerships, staff retention, and understanding behaviour.

www.ipwso.org/news-events/ppconference2024/workshop-summaries



Dr Maryssa Portelli - Guiding Mental Health Presentations in the Emergency Department

This is a must-watch session!

Dr. Maryssa Portelli is a staff-specialist psychiatrist at the RPAH PWS Clinic and Emergency Psychiatry Service in Sydney. Watch here: <https://youtu.be/iwXRwgoEvY>



A New Zealand family's story of transition...



Karen O'Reilly is our IPWSO Parent Delegate and shared this presentation at IPWSO's recent Family Meeting. It is the story of Karen's son moving from home into a residential service, supported by [Spectrum Care](#) in Auckland. This is a helpful video for both providers and families whose children are transition age. www.youtube.com/watch?v=f4rRhAsbUE0

IPWSO Family Meetings

IPWSO began their Family Meetings in 2023 and have held 2 per year. Information sessions are presented on topics relevant to families and community discussion is invited. Each meeting focuses on a different area, with the most recent meeting being on '[Progressing from Childhood to Adulthood](#).' In addition to Karen's presentation above, other presentations included Capacity and Decision-Making, and Navigating Friendships, Relationships & Sexuality.

Previous meetings topics are:

[Managing Challenging Behaviour](#)

[Having a Brother or Sister with PWS](#)

Please check out some of the resources on the pages above.

Dates for your Diary

IPWSO Caregivers Forum - Fri 24th January 8am, online

Camp registration closing - Fri 24th January

PWSA(NZ) Family Support Camp - Fri 21st - Sun 23rd March, Taupō

IPWSO Conference, Phoenix, USA - 24th - 28th June, 2025