

DECEMBER 2025 NEWSLETTER

PWSA(NZ) Committee News

This will be our last newsletter for the year so we would like to wish everyone a safe, happy and restful holiday season. It's been a busy year for PWSA - we developed our [Strategic Plan](#) for the next 5 years, made a start on several projects, and have exciting plans for the year ahead. The first event planned for next year is a Young Families Weekend for whānau who have children age 10 and under - please remember to send your Expression of Interest if you haven't already done so.

We would like to say thank you to Shannan Crow for selecting PWSA as his chosen charity in the Earth Sciences NZ staff photography competition. Shannan's photo won and secured \$1000 prize money for PWSA! Thank you to everyone who voted too.

Changes will continue to take effect in Disability Support Services over the next year. Some of the changes include a new system being introduced for initial NASC assessments and budget allocations from February, and a pause on reassessments for existing users until October. We will be keeping a close eye on these changes. Please let us know if any new issues with your NASC arise.

ALPWS Leadership Group Update

The ALPWS Leadership Group met again in November, and the discussion topic was hobbies. Through polling we discovered that the group's favourite hobbies were swimming and Special Olympics. We also looked at the wide range of hobbies available to try - I wonder if anyone will have tried anything new before our next meeting?



The group also agreed to a renaming! Sometimes people are not sure what ALPWS means so we decided to go for a distinctive and memorable name, "The Ruru Group".

Our group will also be internationally recognisable now because there are OWL (Our Way of Life) groups in other countries.

Group representation was also discussed, and this will be a one year term for a chosen representative from 2026. We would like to thank James Robinson who has been the group representative until now. The RURU Group will act as an advisory group to the PWSA(NZ) Committee, so part of the group representative role is feeding back thoughts and ideas to the Committee when they meet every 2 months.

The next RURU Group meeting will be held in January, but date and time is dependent on survey results. We would love to see more adults living with PWS be able to attend these meetings, so please let us know the best times for you.

Please complete this quick survey > <https://forms.gle/qNMYdqyLHfekdJts7>

Experiences of whānau Māori and PWS

We would like to remind you about research being conducted by Aaron Hāpuku at the University of Canterbury, which will investigate the experiences of whānau Māori and Prader-Willi syndrome.

Participant whānau are needed for this research and if you are interested or have questions you are encouraged to make contact with Aaron as below:

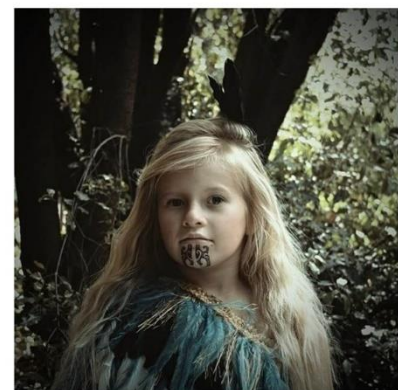
aaron.hapuku@canterbury.ac.nz

Koha will be offered to participant whānau for sharing their time, kōrero and pūrākau (stories, narratives). Data for this project will be collected through wānanga (whānau interviews), interviews and PhotoVoice (photographs/artwork).

Participant whānau needed for research investigating the experiences of whānau Māori and Prader Willi Syndrome.

This research study is being conducted as part of the requirements for the Doctor of Health Sciences (DHSc) degree through the University of Canterbury Faculty of Health | Te Kaupeka Oranga

Whānau with a Prader Willi Syndrome whānau member residing in Aotearoa, New Zealand are encouraged to make contact



Koha will be offered to participant whānau for sharing their time, kōrero and pūrākau (stories, narratives) on the experiences of whānau Māori who live with Prader Willi Syndrome.

Data for this project will be collected through wānanga (whānau interviews), interviews and PhotoVoice (photographs/artwork).

This study has been reviewed and approved by the University of Canterbury Human Research Ethics committee and has undergone UC Māori ethics consultation

If your whānau, or someone you know might be interested, please contact: Aaron Hāpuku
aaron.hapuku@canterbury.ac.nz
<https://profiles.canterbury.ac.nz/Aaron-Hapuku>



A note about appetite suppressants

It has been brought to our attention that some doctors are suggesting a prescription of semaglutide / Wegovy (known as Ozempic overseas) for patients with PWS to help with weight loss. Wegovy is available but not funded in New Zealand, so this treatment is at patient cost.

Whilst semaglutide is known to be more effective for weight loss than the funded type 2 diabetes treatments of liraglutide (Victoza) and dulaglutide (Trulicity), there has not been a clinical trial for safety in PWS and there are known side effects which can be serious without careful monitoring.

For Prader-Willi syndrome, there is particular concern about one of the ways this group of medications act to suppress appetite. These medications slow the rate at which food leaves the stomach which means people feel full for longer, but it is important to consider that gastric emptying already tends to be slow in PWS and there are well known gastrointestinal risks if someone were to continue overeating with a full stomach.

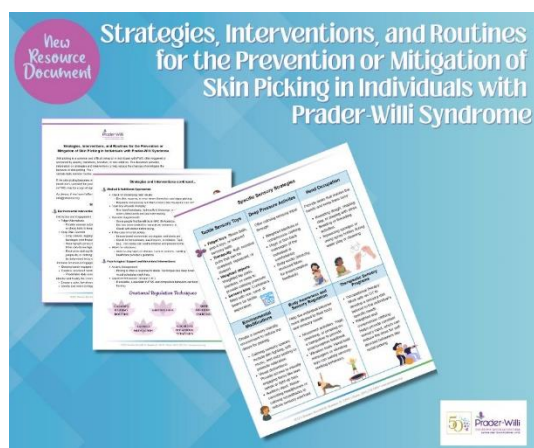
Hopefully, more will be known about the safety of these treatments in time. Assoc Prof Tania Markovic at the University of Sydney is currently investigating Tirzepatide (Mounjaro) which is a similar medication to those listed above. This will be very useful information, especially as Mounjaro is currently being considered for approval in New Zealand.

In the meantime, we would advise caution and discussing at length with your specialist.

We also recommend reading and sharing the recommendations of a clinical workshop convened by FPWR to discuss the efficacy and safety of GLP-1 agonists in PWS.

[Read more about these recommendations here >](#)

New PWS Resource Alert



Strategies, Interventions, and Routines for the Prevention or Mitigation of Skin Picking

A useful new resource from PWSA(USA) that contains lots of tips.

[Click here to read and download >](#)

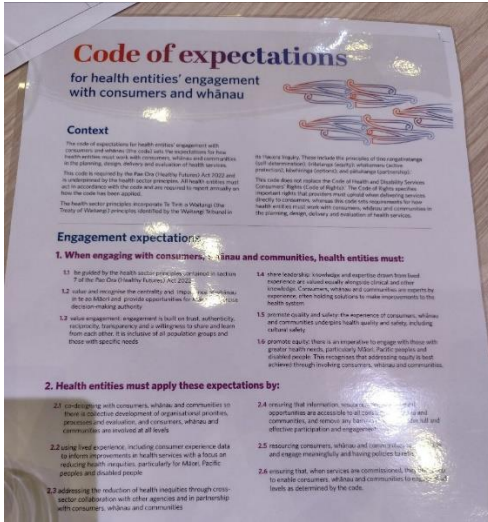
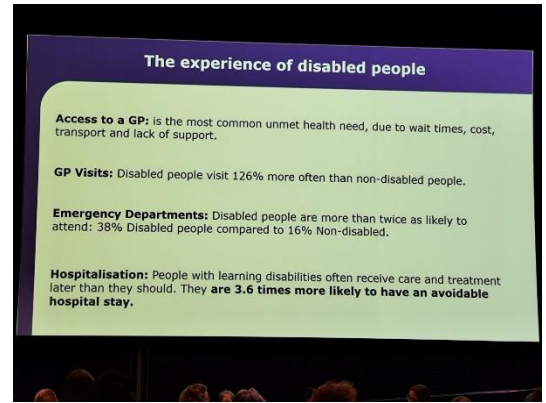
Advocacy Update - Submission to Pharmac

PWSA has made a submission to PHARMAC on their proposal to decline some of the medicines on the Options for Investment list. Growth hormone for adults living with PWS is currently on this list awaiting funding, but we do not know whether it has a high or low priority rating because Pharmac do not share this information.

Pharmac are proposing to decline medicines that have been in the lowest-ranked group for more than two years. This would apply to the bottom 20% of applications (if there are more than 100), or the bottom 10% (if fewer than 100).

PWSA strongly opposes this proposal and would like greater transparency about medicine funding decisions instead. We disagree that removing the bottom 10-20% of the lowest ranked medicines from the OFI list is the right way to achieve the stated goal of creating greater transparency and clarity to how medicine funding applications are managed. [Click here to read our submission >](#)

Ō Mātou Reo: Our Voices 2025



At the end of October, I attended the Health Quality and Safety Commission Our Voices 2025 conference in Wellington.

The conference provided information and insight into how we can expect to work health entities in future when asking for improved health services for people living with PWS.

The code of expectations for health entities' engagement with consumers and whānau can be [found here >](#)

Rare Disorders Strategy to be implemented!

At the end of November, we heard fantastic [news](#) that significant progress has been made on the implementation of the Rare Disorders Strategy. There is great hope that the strategy will help improve health system support for rare conditions like PWS. We would like to thank Rare Disorders New Zealand for their tireless work advocating for the rare disorders collective in making sure this happened. Thank you also to everyone who helped by signing and sharing the petition.

Click here to [read the Rare Disorders Strategy >](#)



Next IPWSO Professional Caregivers' Forum

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 >](#)

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Contact Us:

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