



## December 2023 Newsletter



We would like to wish you all a very merry Christmas and a happy and healthy New Year. It has been another busy year at PWSA in which we ran 2 large events - our National Family Camp at Lake Taupo and the Adults Living with PWS Weekend in Auckland. We have also continued advocacy work by making submissions on proposed law changes and medicines, providing feedback to draft stages of the Rare Disorders Strategy being developed by

the Ministry of Health, and speaking at Parliament about experiences of unmet needs. A landmark occasion this year was when James Robinson became the first person to join our Association Board living with PWS. James will be able to act as a spokesperson for the Adults living with PWS (ALPWS) group who have continued to develop leadership and self-advocacy skills this year and now aim to meet via Zoom on a regular basis.

This year has of course also been a very sad year in which we have lost 3 members of our PWS community, Jacob Davies, Yvette Gaudion and Hannah Vining, plus also the loss of David Bates in December last year. They are always in our thoughts and in their memory we carry on in efforts to try and prevent further loss of lives too soon.

## ALPWS Leadership and Social Weekend



Our second [ALPWS weekend](#) was attended by 21 adults living with PWS and great fun was had by all. A videographer also attended the weekend and was able to capture footage during the weekend, in addition to the planned filming of particular sessions, such as advisory panel work, role playing scenarios, and individual interviews. We look forward to being able to share some of the footage captured with you next year, which we also hope will be useful material for advocacy, raising awareness and training sessions.

Thank you to everyone who joined the 'live' Advisory Panel session to ask the group questions. This was a trial run at this type of work and we hope to be able to develop this more in the future. Also, a big thank you to everyone who came along to the weekend in a support role, and for helping Cindy and Mike with running the weekend.

## Save the date!

We are pleased to announce that the [6th Asia Pacific PWS Conference](#) is being held in Sydney, 30-31 August 2024. This will be a 2 day conference incorporating both a scientific research focused day, plus focused sessions for healthcare professionals, those working in a support role for people living with PWS, and for parents / families.

Confirmed featured speakers are Dr Deepan Singh and Prof Tony Holland. Full programme details coming soon.



We encourage anyone to attend who wants to learn more about Prader-Willi syndrome, including the latest in research, treatments, and care guidelines. This conference provides an excellent opportunity to connect with researchers, clinical experts, allied health professionals, and those working to support people living with PWS, from around our region and internationally. For professionals and support agencies it provides an opportunity to share expertise with others in the health and disability support sectors.

If you would like to attend from New Zealand, please [contact us](#) for further details and to register your interest.

## Seasonal Tips

We all enjoy the excitement and cheer of Christmas, but it's important to remember that for those living with PWS, this time of year can bring increased anxiety too. This may be due to expectations about food or gifts, and anxiety about whether these will be realised. Or changes in routine, environment, noise levels and groups of people may be too overwhelming.



### How can we make Christmas easier?

Families often have rules, limits and plans in place to ensure that everyone experiences an enjoyable Christmas - please check in with the family about their approach, discuss food arrangements beforehand, and support the family in their choices.

Click here for some [seasonal tips](#) to help with Christmas Day planning.

## PWSA Education Survey

This is a reminder of the email recently sent to parents (of present and past pupils).

Please take a moment over the holidays to complete our [Education Survey](#). We are concerned that we appear to be hearing more frequently of pupils being turned down for funding or having their supports reduced or cut completely, but we need clear evidence in order to advocate for change with the Ministry of Education. The purpose of our survey is to gather data and information about any supports received or declined, in particular ORS and SHHNF.

It is important for us to include past pupils in this survey because this will allow us to track any changes in the levels of support provided to pupils with PWS over time.

Survey Link: <https://forms.gle/gxCt6VCugJWKD6QVA>



Prader-Willi Syndrome Association NZ



Teachers' Pack



## PWSA Resources

At the end of the school year we always remind families of the availability of Teacher Packs. These are especially ideal if your child is starting a new syndicate or school next year.

If you would like to order a free pack, please [send us an email](#) or use our [resource order form](#). Packs will be posted out from mid-January.

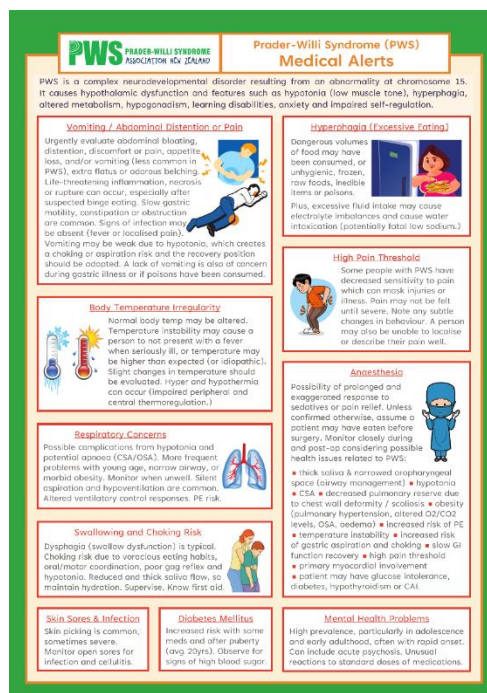
An online version of the pack can be downloaded from our resources page. The pack also contains an editable A4 pupil profile template to share with school staff and relievers which can be downloaded from our [School Support page](#).

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

With frequent staff 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.



## Update on Growth Hormone Funding for Adults

Growth hormone funding for adults living with PWS has now been approved by Pharmac's Endocrinology Specialist Advisory Committee and this was ranked on Pharmac's options for investment list at a prioritisation meeting earlier this month. Pharmac state that they are currently unable to provide a timeframe for when, or if, a decision to fund somatropin for adults and adolescents would be made and that priority of funding options can change over time depending on various factors, including the funds available. We will continue to apply pressure for funding to be approved.

## Testosterone Treatment Submission to Pharmac

Those who use testosterone treatments will be aware that Andriol capsules were discontinued and replaced with Steril-Gene brand under section 29 (for medicines not approved by Medsafe), and that the prescribing of Steril-Gene is limited to those who were prescribed an oral testosterone treatment before 1 November 2021. Oral testosterone is usually the preferred method of administration in PWS because:

- Testosterone patches and gel may be unsuitable for some people with PWS who experience a higher level of sensory issues.
- Testosterone patches and gel can cause skin irritation which may exacerbate skin picking issues.
- Testosterone injections may be unsuitable for some people living with PWS due to mood stability issues being exacerbated by peak highs and troughs of hormone levels. Families also worry that injectable testosterone does not allow for stopping treatment quickly if behavioural problems do occur, and it is therefore recommended by experienced clinicians to initiate treatment in PWS patients with a daily, low dose alternative.

- The application of testosterone gel may cause issues of transmissibility if it needs to be applied by someone else. For adults who live in supported living residential environments, the application of gel by support staff also raises various issues.

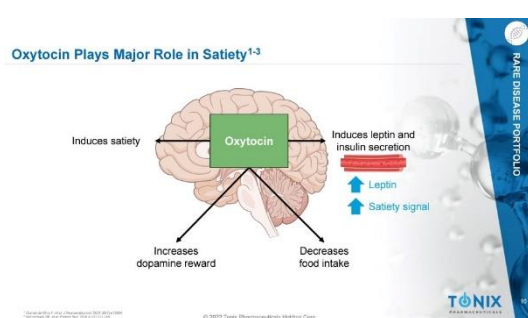
Pharmac recently sought feedback on their proposal to fund testosterone gel and to award Principal Supply Status to Testogel. The PWSA has made a submission requesting that a tablet / capsule form of testosterone is an available option to new patients starting testosterone treatment. We also checked with Medsafe about the reasons why Steril-Genie is not approved and they responded that they have not received an application for Steril-Genie and they therefore hold no formal data relating to the quality, safety, and effectiveness of the product.

Therefore, it is somewhat reassuring that an application has not been declined and we are currently not aware of any known safety concerns specific to the Steril-Genie brand.

## Research Update - New Carbetocin Trials

There is much excitement about the new phase 3 trial of carbetocin which has just been initiated by Acadia Pharmaceuticals ([COMPASS PWS](#)). Intranasal carbetocin is the closest oxytocin-like therapeutic option to being approved for use in PWS.

In June 2022, Acadia acquired Levo Therapeutics and worldwide rights to ACP-101 (carbetocin) and then met with the FDA on the design of a new trial addressing the FDA's concerns. In 2021, the negative vote by the FDA in the review of a New Drug Application for LV-101 (carbetocin) had surprised many in the PWS community, especially considering the combined efforts of Levo Therapeutics, FPWR, PWSA(USA) and families to support the application, including compelling testimonies given by families involved in the trial. Positive results were observed on hyperphagia, anxiety and distress symptoms at the lower 3.2mg dose in the phase 3 (CARE-PWS) trial and during the extension study, but the FDA had efficacy concerns and requested an additional study to confirm results for this dose.



Another trial of intranasal oxytocin will also be starting soon as Tonix Pharmaceuticals have announced clearance from the FDA for their [Phase 2 study of TNX-2900](#) to treat PWS in children and adolescents. Tonix's OT formulation combines oxytocin with magnesium for improved receptor binding and potentially improved therapeutic action.

## 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](#).

# Notices / Events

## Dates for your Diary

PWSA Education Survey – Closing Jan 31st, 2024

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

Next IPWSO Conference - USA, 2025!

Many regional events and workshops are now being presented online.  
The following websites can be checked for future dates.

[Imagine Better Workshops](#) - i.e. Making Individualised Funding Work, and other workshops for families, service providers or people with disabilities

[Care Matters Workshops](#) - i.e. Explore-Learn-Connect, Transitions

[Parent to Parent Courses and Workshops](#) - i.e. Navigating the System, Renew-Connect-Reflect

[Disability Connect Workshops](#) (Auckland) - i.e. Education Legal Issues, IF, Transition, Planning for Adulthood, Living Options, WINZ, (*\$20 per family*)

[Parent to Parent branches for local support group meetings](#)

[Sibling Support Programmes](#) - SibShops and Camps are advertised on the Care Matters and Parent to Parent calendars.



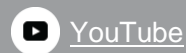
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