



July Newsletter

SAVE THE DATE! We have two important dates for you!

SAVE THIS DATE FOR THE BIGGEST PWS EVENT OF THE YEAR!

The 5th Asia Pacific Prader-Willi Syndrome Live Webinar

Conference is happening on **29th to 31st October 2021**

5TH ASIAPACIFIC Prader-Willi Syndrome Conference
One Voice Together

	Focus on Science Friday 29.10.21 LIVE Webinar	Focus on Care & Support Saturday 30.10.21 LIVE Webinar	Hear Our Voices Sunday 31.10.21 LIVE Webinar
India	6.30AM to 10.30AM	6.30AM to 10.30AM	6.30AM to 10.30AM
Thailand Vietnam	8.00AM to 12.00PM	8.00AM to 12.00PM	8.00AM to 12.00PM
Malaysia Singapore	9.00AM to 1.00PM	9.00AM to 1.00PM	9.00AM to 01.00PM
Indonesia Philippines	9.00AM to 1.00PM	9.00AM to 1.00PM	9.00AM to 01.00PM
Taiwan Hong Kong	9.00AM to 1.00PM	9.00AM to 1.00PM	9.00AM to 1.00PM
China	9.00AM to 1.00PM	9.00AM to 1.00PM	9.00AM to 1.00PM
Japan South Korea	10.00AM to 2.00PM	10.00AM to 2.00PM	10.00AM to 2.00PM
Australia AEDT	12.00PM to 4.00PM	12.00PM to 4.00PM	12.00PM to 4.00PM
New Zealand	2.00PM to 6.00PM	2.00PM to 6.00PM	2.00PM to 6.00PM

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[PWSAus](#) | [Prader-Willi Syndrome Association NZ](#) | [Parasatuam Sindrom Prader-Willi Malaysia](#) | [Prader-Willi Syndrome Association Thailand](#)

Joint Organisers: [PWSA](#), [PWS NZ](#), [PWSA Malaysia](#), [PWSA Thailand](#)
 Global Principal Organisations: [IPWSO](#)
 Webcast Host: [webex](#)

The **5th ASIA-PACIFIC PWS CONFERENCE** is being held virtually from **Friday 29th - Sunday 31st October**. This provides an exciting opportunity for both family members and professionals to easily attend a PWS conference without the need to travel overseas. Conference times in New Zealand are from 2pm to 6pm over the 3 days. Programme details will be emailed to you soon and reduced-rate **EARLYBIRD REGISTRATIONS WILL BE OPENING SOON - WATCH THIS SPACE!**

We will also be emailing you soon about families and people with PWS participating in day 3 presentations - an exciting new initiative aimed at giving a voice to the people we support.

FAMILY CAMP 2022. We are also very excited to announce the date of our next family camp! This will be held **11th - 13th March, 2022 at MiCamp Taupo**. Our family camps are open to people with PWS of all ages to attend with their family or a support worker. We have decided to hold our camp at Taupo again for a couple of reasons - it was a very comfortable and popular venue, and logistically, it is in the middle of the North Island allowing for the majority of North Islanders to make their own way there by car. There will, of course, be subsidies available for families flying from the South Island. Registrations will be opening later this year. In the meantime, save the date, and if you are in the South Island, you may want to take advantage of any advance booking flight deals.

Tweens and Teens Weekend

We really enjoyed seeing some of our teens back together again and it was lovely to see some new tweens joining the group. These weekends prove to be valuable experiences for both teens and parents alike. [Click here](#) to read more about the weekend and to view some more pictures.



A feedback survey has been sent to families who attended. Feedback is useful for planning future events, but it is also good to include in grant accountability reports and in any future funding requests. If you haven't sent feedback already, would you please consider completing this brief form:

<https://forms.gle/GVp75hUr7j8qSear8>



PWS Training Workshops - Please see webpage for new details.

A reminder that the PWS training we offer to support providers and schools has recently been revised. This was mainly because we now have an additional option of online training via Zoom, which has proven to be a successful and often more flexible way of delivering training. Please view and share our [Training Courses page](#) which contains full details of the different workshops available, new pricing details, and a booking request form.

Flu and Covid-19 Vaccinations Reminder

PWS is classified as an underlying health condition and disability which is considered a priority for Covid-19 vaccinations, alongside vaccinations for residential care staff and carers of disabled persons. Vaccinations for PWS are being offered in [phase 3](#) and you should have received a notification from your GP / local health centre about when the vaccine will be offered to you.

As usual, the [annual flu vaccine](#) is available for people with PWS, but this year it is important to consider the timing with Covid-19 vaccinations, as they need to be given at least 2 weeks apart. Therefore, if the flu vaccine is given first, the first Covid-19 vaccination can be given from 2 weeks later, but if a Covid-19 injection is given first, the flu vaccination cannot be given for at least 5 weeks following the 2nd Covid-19 injection.

Thank you to SKOPE Industries Christchurch and Glenn Myall

Glenn Myall is Dad to 10 year old Charlotte who has PWS and he works at SKOPE Industries Ltd in Christchurch, where they held a bake sale to raise PWS awareness and funds for the PWSA. We would like to thank Glenn and his colleagues for their support and generosity. Their bake sale raised a huge total of \$1165.70 - that's a lot of baking!

PHARMAC Review

We have an opportunity to participate in the Government initiated PHARMAC review. This review will focus on 2 areas - how well PHARMAC performs against its current objectives, whether those objectives maximise its potential to improve health outcomes for all New Zealanders, and if these should change and how. It can be a notoriously lengthy and difficult process to obtain funding approval for rare disorder medicines within the current funding model, as many PWSA members will know having experienced the long battle to achieve access to GHT at the level it is funded today, yet this is still not on a par with other comparable countries. When new treatments become available for PWS, we may face similar battles. Applications for new medicines by rare disorder groups are often not reviewed equitably, partly due to lower study participant numbers and the higher cost of medicines for smaller user groups. With a lack of rare disorder representation on the review panel, it is essential that we make our voice heard. The PWSA(NZ) will submit a collective response on behalf of our members, but individuals are also able to make a submission, so please consider sharing your views. Alternatively, please email us any views to be included in our collective PWSA response. Please contact us by Wednesday 14th July as submissions close FRIDAY 16 JULY at 8pm.

Follow this link to [use the online form or download the form in Word format >](#)

The review will consider a range of factors, including:

- * the timeliness of PHARMAC's decision making (in particular for new medicines)
- * the transparency and accessibility of decision-making processes
- * equity, including access to medicines and devices for Māori and Pacific peoples.

Within the scope of the review will be how PHARMAC uses its budget to achieve the best possible outcomes. Out of scope will be the fixed nature of the budget and the total amount allocated to pharmaceuticals by the Government.

New Resources - Guides for Doctors

IPWSO's Clinical and Scientific Advisory Board have produced some excellent new guides for doctors and health practitioners to aid the medical evaluation of patients. They provide an overview of the most common and serious medical issues affecting people with PWS and have been written for 4 different age groups.

Families may wish to take these to appointments with them and we will certainly be putting guides into our New Parent Pack and the new pack we are developing for providers supporting adults with PWS. [Download your copy here >](#)



IPWSO
International
Prader-Willi Syndrome
Organisation

Education Advocacy

Rare Disorders NZ have invited us to participate in a first phase of engagement in the 'Review of Interventions for Students with the Highest Level of Learning Support Needs', as the Ministry of Education are seeking feedback from rare disorder groups and disability organisations. This initial engagement is to co-design and agree on the scope and terms of reference for this review and is taking place via a series of Zoom meetings. Please contact us if there are any key areas you would like to see identified and considered in this review.

Research and Medicines Update - Carbetocin

There has been lots of excitement surrounding the various oxytocin trials over the last decade. One which has been generating the most interest is an oxytocin-like drug called carbetocin, developed by Ferring Pharmaceuticals originally and then purchased by Levo Therapeutics. A New Drug Application for LV-101 (intranasal carbetocin) has just been granted Priority Review by the FDA (the agency which regulates and approves drugs in the USA) for the treatment of hyperphagia and behavioural symptoms in PWS. An FDA decision on approval is expected by the end of the year!

Oxytocin is a hormone which is released from the hypothalamus and associated with maternal care, bonding, feeding in infancy, social cognition, OCD, anxiety and appetite control. A reduction in the number of neurons that produce oxytocin and reduced oxytocin receptor gene expression in PWS are believed to be associated with the social-emotional and appetite behaviours of PWS. However, early oxytocin trials produced conflicting and sometimes undesired results, but researchers remained optimistic because oxytocin signalling is complex and it was thought that finding the correct formulation and dose would be crucial to the success of oxytocin therapy.

Carbetocin is a synthetic analogue of naturally-occurring oxytocin, designed to specifically bind to and stimulate the oxytocin receptors and have reduced impact on related vasopressin receptors, therefore limiting any unwanted side effects. Statistically significant reductions in hyperphagia and symptoms of anxiety and distress were observed in Levo's CARE-PWS study, in which carbetocin was generally well-tolerated at a 3.2mg dose in the 7-18 year old participants.

The FPWR state that carbetocin is approved in over 90 countries for uterine atony and postpartum haemorrhage (PPH), but this newer analogue of oxytocin is not yet used in NZ, despite studies showing that it is more effective than oxytocin in treating PPH. Currently, only oxytocin is approved by MedSafe in NZ, which is indicated for induction and enhancement of labour, management of the 3rd stage of labour to promote separation of the placenta and reduce blood loss, during caesarian section, and also to prevent and treat PPH associated with uterine atony. LV-101 is an intranasal form of carbetocin, intended to be administered three times daily before meals.

DCCR Update

In our last newsletter, we reported that in their New Drug Application for DCCR in PWS, Soleno Therapeutics had submitted additional analyses revealing how Covid-19 had negatively skewed the results of DESTINY PWS (phase 3 clinical development programme). However, the FDA requested an additional controlled clinical trial, which led Soleno Therapeutics, PWSA(USA) and FPWR to ask that the FDA reconsider the need for this additional trial and request that robust pre-pandemic findings were not dismissed. They collected and compiled the experiences of patients and caregivers during the completed DESTINY PWS trial, and the ongoing C602 open-label study, and sent this information to the FDA with their request.

Soleno have now announced that the FDA have agreed to evaluate additional data from their DESTINY PWS and long-term, open-label extension study, C602. The FDA have not ruled out that an additional trial may be necessary to assess safety and efficacy to support a NDA, but Soleno are appreciative of the opportunity to submit supplementary data and to include patient voice in their discussions.

DCCR is thought to affect leptin pathways by opening KATP channels and also to improve GABA signalling. [Trial results](#) have shown meaningful improvements in hyperphagia, decreases in body fat and improvements in aggressive and destructive behaviours.



New Zoom Times Reminder

Zoom meetings for adults with PWS are now taking place on the 1st Tuesday of each month at 4pm. Zoom meetings for tweens and teens have also been changed to 4pm, still on the 2nd Saturday for now. Links and password remain the same. Details can always be found on our [events page](#) and on Facebook.

Dates for your Diary

Zoom Chat for Adults with PWS - Tuesday 3rd August, 4pm

Zoom Chat for Tweens and Teens - Saturday 14th August, 4pm

Virtual Social Evening for Parents of 6-12 year olds - Sun 29th August, 7.30pm

Transition Expo 2021, Auckland - 8th September

Young Families Weekend - September 2021, date TBC, Wellington

The 5th Asia Pacific PWS Conference - Fri 29th - Sun 31st October 2021

PWSA(NZ) Family Camp - 11th-13th March 2022

Notices / Events

Planning for Adulthood: The Legal Framework

Aug 9th, Sept 22nd (Zoom), Oct 13th (Zoom), Nov 10th - Auckland venues or Zoom
by Disability Connect

Formerly known as Trust and Welfare Guardianship seminar. RSVP essential.

Click here for [further details and booking >](#)

Safeguarding the Future

August 25th, 11.30am - 1pm - Webinar

by Imagine Better

If you have ever asked yourself, 'What will happen when I'm no longer here?' this one and a half hour free webinar would be a good investment of time.....

Click here for [more information and registration >](#)

Annual Transition Expo 2021

September 8th, 9am-2pm - Auckland Netball Centre, St Johns

by Disability Connect, supported by MSD and Geneva Healthcare Opportunities and advice from Transition, Vocational, Recreation, Activity and Information Providers. For all students with a disability and those involved in the disability sector.

Click here for [more information >](#)

How to Get the Most Out of Your NASC - Taikura Trust

'Tips for Positive Engagement' - September 30th and October 28th

by Disability Connect

Even after many years of engagement with the NASC, individuals and their families can remain frustrated, uncertain and even angry and upset. Understanding how the NASC works, its functions and how to engage positively with the staff who are the face of the system, enables people to achieve much more positive outcomes.

Click here for [further details and RSVP >](#)

Many regional events and workshops are being presented online at the moment. 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.