



September Newsletter

5th Asia Pacific PWS Conference - Live Webinar - Oct 29th - 31st

Only 2 weeks remain to [register!](#) This conference provides an exciting opportunity for both family members and professionals to easily attend a PWS conference without the need to travel. Conference times in New Zealand are from 2pm to 6pm each day. Day 1 has a focus on science, day 2 focuses on care and support, and day 3 provides a voice to people and families living with PWS (thank you for your amazing video contributions.) We have terrific speakers presenting on key topics and issues, including from New Zealand: John Taylor of Community Connections and PWSA's Cindy Adams-Vining, behaviour specialist and psychologist, Dr John Ford, plus PWSA board member and Speech and Language Therapist, Hayley Arnott.

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

The 5th Asia Pacific Prader-Willi Syndrome Live Webinar

5TH ASIAPACIFIC Prader-Willi Syndrome Conference
One Voice Together

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

	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

ppws2021@gmail.com
 PWSA: Prader-Willi Syndrome Association NZ | Peratuan Sindrom Prader-Willi Malaysia | Prader-Willi Syndrome Association Thailand
 Joint Organisers: PWSA, PWS, and others | Global Advisory Organisation: IPWSO | Webinars Hosted by: webex

Have you registered yet? [FURTHER INFORMATION AND REGISTRATION HERE >](#) Don't miss this opportunity! (Please note: Conference recordings will be available post conference to registered attendees.)

PWSA Family Camp: 11th - 13th March 2022

Have you saved the date of our next family camp? This is being held at the popular MiCamp Taupo once again. Our family camps are open to people with PWS of all ages to attend with their family or a support worker and there will be subsidies available for families flying from the South Island. Registrations will be opening soon, but in the meantime, you may want to take advantage of any advance booking flight deals.

Thank you Alwyn!

Sadly, we have had to say farewell to our valued Treasurer, Alwyn Jones, who has moved on to other projects. As board member and Treasurer, Alwyn has put in many volunteer hours, and contributed enormously to our organisation over the past 5 years. He has left us in a better place and we are all very grateful for his time and efforts.



Thank you to Richard Fletcher!

Richard lives in Christchurch and is supported by IDEA Services. During PWS awareness month, Richard decided to sell ribbons and wristbands to create PWS awareness and raise funds for the PWSA.

We would like to thank Richard for his fantastic efforts!

New Resources - Guides for Doctors

These guides feature in our newsletter again, in case you missed them, as they are an excellent new resource. Produced by IPWSO's Clinical and Scientific Advisory Board, they are designed 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.

[Download your copy](#) to take to appointments with you. We will certainly be putting guides in our New Parent Pack and the new pack we are developing for providers supporting adults with PWS.



IPWSO
International
Prader-Willi Syndrome
Organisation

PHARMAC Review Update

The PWSA submitted a response on behalf of members to the Government review of PHARMAC, which is focused on 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.

The release of an interim report by the Minister of Health is currently overdue, but there is some good news in that the review panel have requested Rare Disorders New Zealand provide them with more information on international models for rare disease medicines, along with a request to speak with some experts from other countries where rare disease medicine assessment is working well.



New Zoom Times for Adults!

At the request of those attending a recent meeting, the Zoom meetings for adults with PWS are now taking place on Saturdays. They are held on the **1st Saturday of each month at 4pm**. Details and links can always be found on our [events page](#) and on Facebook. **NEXT MEETING THIS WEEKEND!**

Mental Health Awareness Week

As it is Mental Health Awareness Week for Aotearoa, we thought we would share with you some of the latest mental health resources for PWS.

- ['Behaviour and Mental Health' presentation](#) by Prof Tony Holland for IPWSO's Health ECHO Project
- [Mental Health Guidebook](#) - a downloadable web page by FPWR
- [Serious Mental Health Problems in Prader-Willi Syndrome](#) - a downloadable web page by FPWR
- [Pharmacodynamic Gene Testing in Prader-Willi Syndrome](#) - research by Janice Forster, Jessica Duis and Merlin Butler
- [Mental Health web page](#) - information by Prof Tony Holland via IPWSO
- [Mental Health web page and links to further resources](#) - PWSA NZ
- [Mental Health Overview](#) by PWSA USA

Dates for your Diary

Zoom Chat for Adults with PWS - Saturday 2nd October, 4pm

Zoom Chat for Tweens and Teens - Saturday 9th October, 4pm

Virtual Social Evening for Parents of Teens and Adults - Sun 17th October,
7.30pm (brought forward due to APPWS conference)

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

Transition Expo 2021, Auckland - Wednesday 10th November

Young Families Weekend - new date Sat 13th - Sun 14th November, Wellington

Virtual Social Evening for Parents of 6-12 yr olds - Sun 28th November, 7.30pm

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

Notices / Events

Disability and Adulthood

October 4th, 5th and 6th, 7pm- 9pm - via Zoom

by Parent to Parent

3 part series. [Register here](#). topics include:

- Creating a vision for the future
- Circles of support
- Supported decision making
- Legal capacity
- Welfare guardianship
- Wills, trusts and enduring powers of attorney

Planning for Adulthood: The Legal Framework

Oct 13th 6.30-9.30pm (Zoom), Nov 10th - Otahuhu

by Disability Connect

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

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

Annual Transition Expo 2021

November 10th, 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 >](#)

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.