

September 2024 Newsletter

Kia ora and Happy Spring!

As the end of the year approaches, we have a few diary date reminders for you.

A social event for parents in the Auckland region is planned for the evening of **Saturday 19th October**. If you would like to get together over drinks and dinner, please [click here](#) to book as soon as possible.

It would be fantastic to see some 'get togethers' happening in other regions too - please get in touch if you would like to organise an event so that we can discuss funding availability and share the details for you.

Did you mean to register for the Transition Symposium? Please do so ASAP as registrations must close: www.trybooking.com/nz/TSP

Have you saved the date for our Family Support Camp next year? This is taking place **Friday 21st - Sunday 23rd March** at MiCamp Taupo. As usual, people of all ages with PWS are welcome to attend with their family or a support person. Although this will be the 3rd camp held at Taupo, next year's camp promises to be different, with some exciting new ideas being developed by the organising committee! Our [ALPWS Leadership group](#) will be invited to a Zoom meeting soon to discuss your ideas and input to the planning and running of camp.

Transition Symposium

October 18th and 19th
Mount Richmond Hotel, Auckland

Support Agencies / Providers Friday 9.30am - 4pm	For Families Saturday 10am - 5pm
<ul style="list-style-type: none"> Overview of PWS and the transition phase in PWS. The impact of PWS and adolescence on transitioning. Support for families. Creating opportunities, facilitating inclusion and enabling aspirations. Balancing rights and independence with health and safety. Tips for transition to a residential support service. Working together. Importance of good health and mental wellness during transition. When things go wrong. 	<ul style="list-style-type: none"> What is transition and why are we talking about it? What science, research and experience tells us. Entitlements, accessing support and making it work. Employment and opportunities. Balancing rights and independence with health and safety. Tips for transition to a residential support service. Financial arrangements, supported decision making and guardianship. Transitioning to adult health services. PWS and mental health. When things go wrong.

RECOMMENDED FOR: SUPPORT PROVIDERS, NASCS, TRANSITION SERVICES, VOCATIONAL SERVICES, AND MORE...

Register here:

www.trybooking.com/nz/TSP

Includes lunch, morning and afternoon tea.

PROF / AGENCIES \$95pp

FAMILIES \$75pp or \$140 for 2 parents





Sponsored by IPWSO and Friends of IPWSO(USA)

New Initiative - IPWSO Caregivers' Forum

A place for professional PWS caregivers worldwide to share practice-driven knowledge, information and support.

The Caregivers' Forum is a virtual space for PWS caregivers to connect and collaborate. The Forum is supported by the [Professional Providers and Caregivers Board](#) (PPCB) of IPWSO, an advisory board dedicated to sharing best practice, information, knowledge and strategies to those supporting the global PWS community.

Would you like to join the forum? The next meeting is being held **Friday January 24th at 8am (NZ time)**.

There will be 3 meetings per year which last for 90 minutes each. IPWSO will facilitate:

- 3 Caregivers' Forum meetings annually
- 3 Forum newsletters following meetings
- A webpage for the Forum which includes latest news and shared resources
- Ad-hoc support for networking in your own country

For more information, please see the [information booklet](#).

Click here to [join the forum](#) and complete a short form. After joining, you will receive invitations to meetings, newsletters and shared resources.

Spread the word by downloading and sharing the information booklet with your colleagues, or your support network.



Disability Support Changes

There has been significant change to disability support funding this year, initially with how families could use their funding, and now with a freeze on residential support funding and the availability of new placements.

Have you or someone you assist had a recent NASC assessment or review? Have you been waiting for residential support?

Carers NZ would like to hear from you if your supports have changed (whether increased, decreased) or stayed the same. Your input helps build an important picture. If you have time, please complete the following survey:

www.surveymonkey.com/r/GYYCHVZ

Petition requesting a Minister or Commissioner for family carers, and the

development of protective legislation, programmes, and services to sustain carers physically, mentally, and financially.

More than a million New Zealanders care for family members and whānau but might feel invisible, taken for granted, or unsupported. The Carers Alliance of 60+ national not for profits is calling for a home in government for family carers, and for action to protect their mental, physical, and financial wellbeing.

If you would like to support this call, please sign and share the petition below:

www.petitions.parliament.nz/390fec4e-437c-45cd-a182-08db3f91e80e

Round-up of APPWS Conference 2024



APPWS2024 took place at the end of August and was a successful, well attended event. Jo Davies, Cindy Adams-Vining, Hayley Arnott and John Ford attended from NZ in presenting / organising roles, plus 2 other in-person attendees from NZ. We hope those who registered virtually were also able to enjoy the experience. Video recordings of the presentations should be sent to all attendees soon.

We are in the process of compiling a full round-up report which will be sent to all inboxes soon. In the meantime, please enjoy 2 new videos which were shown at the conference.



PWSA(NZ) Adults Living with PWS Weekend 2023



Off the Cuff Interviews @ ALPWS Weekend 2023

New IPWSO Resources

Resources from the 2024 International Caregivers Conference are now available online.

8 presentations from the conference are available via [IPWSO's YouTube channel playlist](#). These include:

- Balancing rights and restrictions.
- What is it like to live in a PWS care home?
- Advice from PWS Caregivers Parts 1 - 3

We also recommend these films recorded at the conference:



- [Friends, Partnerships and Sexuality](#) - Patrice Carroll and Neil Gumley
- [Ageing in PWS](#) - Susanne Blichfeldt and Larry Genstil

You can find pdfs of all presentations, where permission is given by the speaker, here on [IPWSO's website](#). These include:

- The future of care for people with PWS - Norbert Hödebeck-Stuntebeck
- Outcomes for persons with PWS in full-time services: findings from international archival data.
- Operationalised list of infrastructure and staff skills required for specialised care of PWS as rated by residential care providers in the USA.
- Ageing - Susanne Blichfeldt and Larry Genstil.
- Staff retention: and what happens when there's a breakdown - Lynn Garrick and Claire Poor-Harmon.
- Understanding Behaviour - Norbert Hödebeck-Stuntebeck and Tony Holland.
- Meaningful Employment for People with PWS - Larry Genstil.

Clinical Trials Registration of Interest Form

We are always looking for opportunities for New Zealanders to participate in clinical trials. A number of things are needed in order for trial sites to be set up, and one of those is access to patient data that enables feasibility to be more easily assessed. We are currently looking at PWS patient registry options, but in the meantime, if you, your child, or the person you support is potentially interested in clinical trial participation for PWS, to please complete our [Clinical Trial Interest Form](#) with details of specialist seen and hospital location.

Rare Disorders Strategy Update

As mentioned in our previous newsletter, we now have a strategy for Rare Disorders which finally recognises the unique challenges and needs of those experiencing rare disorders, and is official recognition that improvements in health system responsiveness are needed. Whilst it is an important first step for building better systems, the strategy did not contain all that was hoped for.



One area missing from the strategy is patient registries to collect data on health outcomes for particular conditions. Once patient records can be coded, this would also enable

standards of care guidelines to be attached to patient records. Another key element missing from the strategy is a Centre of Expertise: internationally-networked experts available to provide expertise and guidance for clinicians and professionals in how to support rare patients in accordance with best practice.

Since publication of the strategy, RDNZ have worked with the rare disorder community to re-confirm the priorities for the strategy. You can read the [7 priorities](#) here. Unfortunately and unacceptably, implementation of the Strategy has been placed on hold whilst Te Whatu Ora undergoes its reset, but RDNZ is in contact with Manatū Hauora as the lead implementation agency who plan to organise a cross-agency meeting in the coming month to discuss next steps.

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

Notices

Dates for your Diary

PWSA(NZ) Transition Symposium - Fri 18th - Sat 19th October, Auckland

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

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