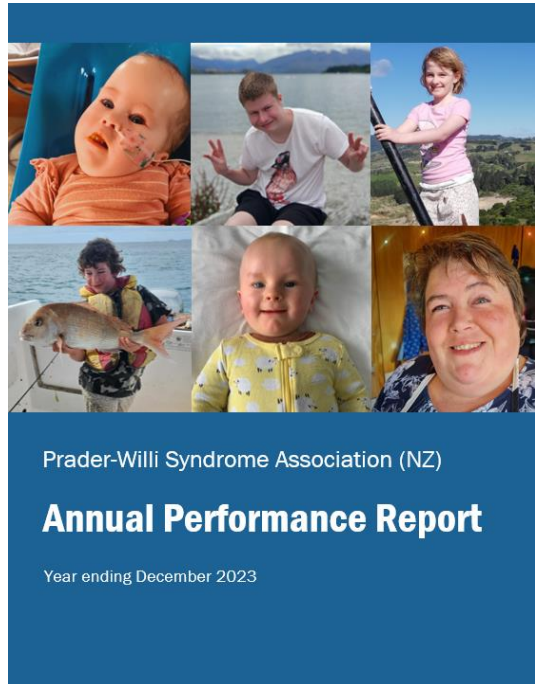


July 2024 Newsletter

Kia ora,

We hope you are all keeping well during these Winter months. If you have concerns about illness and wanted to consider flu vaccination, please don't forget that this is available free of charge for people living with PWS.

The last couple of months have been busier than usual with Awareness Month, our AGM, conference preparation, and various other new and ongoing projects. If you would like to find out more about the work of PWSA(NZ), please see our [Annual Report for 2023](#), which was presented at the AGM in June this year.



During June, we were very pleased to welcome Rebecca Payne to our team. Rebecca has volunteered to take on the role of Young Families Support Coordinator.

We think Rebecca will be fantastic in this role and we are very grateful that the Association can now provide focused support for families at diagnosis and during those early years.

If you would like to get in touch, Rebecca can be contacted via: youngfamilies@pws.org.nz

PWS Awareness Month 2024

Like previous years, we ran an awareness campaign via social media and managed to increase the reach of PWS information posts to almost 13,000 during May. Thank you to everyone who interacted with posts and contributed photos for our PWS spotlight campaign. Awareness was spread in other ways too, with several orders received for merchandise and posters. A special thank you to Richard Fletcher in Christchurch who raised funds by selling ribbons and wristbands, and to Shelley Mitchell who organised an 'orange' day at St.James School in Christchurch, and raised \$658 through the sale of her

amazing orange bracelets and collecting donations. Our new merchandise store was also launched, with products available to be ordered all year round: www.pwsanz.digitees.co.nz



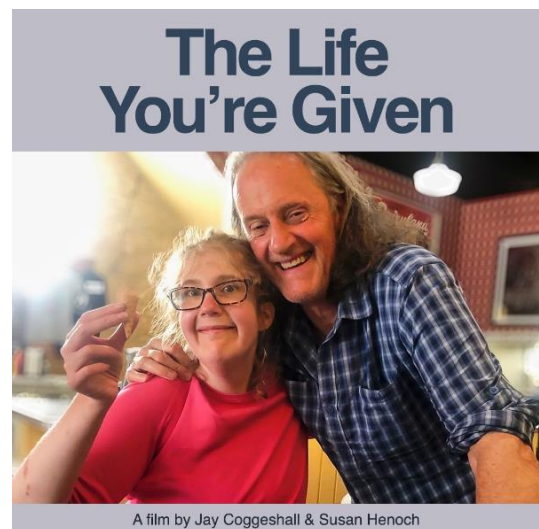
Emily in Nelson, Dekken in Christchurch, Kelly-Ann, and Lee in the Bay of Plenty.



Shelley's bracelets, new Tshirts, and PWS awareness at Educare Taupiri.

During May, we also shared a special matinee screening of 'The Life You're Given' where filmmakers, Jay and Susan, were able to join us afterwards to answer questions. The film raises awareness and understanding of PWS for those unfamiliar with the syndrome, and families were able to feel the connection we all have through our shared experiences. Our screening raised \$1887 for PWS research to date!

A second (evening) screening will be taking place soon - **watch this space for a date announcement!**



Aotearoa New Zealand's Rare Disorders Strategy



We finally have a strategy for Rare Disorders! Published this week by the Ministry of Health, this long awaited document is the result of over two decades of advocacy by Rare Disorders New Zealand. This is a significant milestone for the rare disorder community and an important first step for building better systems for improved outcomes. [Read the strategy >](#)

Whilst this is a moment to celebrate, the strategy does not contain all that we hoped for. One of these areas is patient registries to collect data on health outcomes for particular conditions. There are a number of obstacles to overcome in order to establish patient registries, but inadequate data integration technologies within Te Whatu Ora seems to be the main issue. 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. This was part of RDNZ's vision for the strategy -

internationally-networked experts available to provide expertise and guidance for clinicians and professionals in how to support rare patients in accordance with best practice. We had hoped to establish CoE links to PWS expertise. Meanwhile, we are forging links with the Queensland CoE for PWS.

RDNZ will now be focusing on working with the agencies responsible for implementation of the new strategy to ensure it is adequately actioned. However, they will continue to assert that there is more to be done and that this strategy is the first step in a pathway forward.

Advocacy Update: Adult Decision Making Law

Responses to New Zealand Law Commission's [Second Issues Paper](#) reviewing the law relating to adult decision-making capacity were invited to be submitted in June. A response has been submitted on behalf of PWSA which mainly outlines our concerns with the proposed single test for decision-making capacity which identifies four factors for assessment.

[You can read our submission here >](#)

Asia Pacific PWS Conference 2024



APPWS2024, **Aug 30th-31st**, is fast approaching.

For in-person attendance in Sydney, registration is closing August 15th.

For virtual registration, discount codes have been sent to families in New Zealand. Unfortunately, there has been a technical hitch with the codes which has been resolved today, but families will need to use new codes - keep an eye out for these in your inbox.

Registration is via the conference website: appws.org

Here are some highlights you won't want to miss:

Day 1 (Aug 30th) – Research Day, led by PWRFA

- Dr Deepan Singh - Guanfacine XR for the Reduction of Aggression and Selfinjury in PWS
- A/Prof Olivia Veatch - Elucidating the causes and consequences of sleep disturbances
- Dr Yoon Hi Cho - DCCR for the treatment of PWS
- Dr Tien Lee - Restoring the Gut-Brain Pathways of Hunger Control using ARD-101
- A/Prof Daryl Efron - Does CBD reduce severe behaviour problems in children and adolescents with intellectual disability?

Day 2 (Aug 31st) – Parent, Professional and Support Providers Day

- Dr Deepan Singh – Mental Health & Behaviour: A Review for Families
- A/Prof Tania Markovic – Lifelong Medical Support
- Cate Fox – Healthy Nutrition for Children
- C/Prof Janet Franklin – Healthy Eating for Adolescents and Adults

- Hayley Arnott & Anica Jansson - Encouraging Communication in All Ages
 - Prof Brendon Yee – Sleep Disorders
 - Cindy Adams-Vining - Transition from School
 - Dr Honey Heussler – Centre of Expertise
-

Save the Dates!

We have 2 major new dates coming up that you should put in your diary now!

18TH - 19TH OCTOBER - PWSA(NZ) TRANSITION SYMPOSIUM (Auckland)

Further details to be announced, but this 2 day event will most likely have a day which is more focused on families (Sat) and a day more suited to professionals and providers (Fri). Topics will most likely include preparing for and managing transition from school, moving into a supported residential service, health care during transition, challenging behaviour and mental health support, navigating the system, and much more.

21ST - 23RD MARCH - PWSA(NZ) FAMILY SUPPORT CAMP (Taupo)

We will be returning to MiCamp Taupo once again for our all ages camp. Children and adults living with PWS will be welcome to attend with their family or a support person. Please feel free to send through any ideas for our camp planning committee to consider.

IPWSO's PWS Caregivers Conference 2024



In April, we introduced you to Bjørn Christensen, who is a Regional Service Manager at Community Connections in Wellington. In May, Bjørn travelled to [IPWSO's International PWS Caregivers Conference](#) in Berlin with support from PWSA(NZ) and an IPWSO travel scholarship, kindly sponsored by Friends of IPWSO(USA).

On his return, Bjørn has written a detailed report of his learnings and ideas for development pathways that aim to

enhance supports for adults living with PWS in the residential support sector. Points raised in Bjørn's report could form the foundations of future discussion on strategies for improved support outcomes, and Bjørn is keen to see collaboration between care provider agencies in New Zealand to achieve this. We plan to facilitate the sharing of Bjørn's learning, including at two future events that are currently in early planning stages.

Bjørn also very much enjoyed the opportunity to connect with international support providers and to exchange practice-driven knowledge and ideas. We look forward to fostering Bjørn's continued links this international network, and his future involvement with our Association. Please get in touch if you have any questions for Bjørn.

Clinical Trials Registration of Interest Form

We are currently looking at PWS patient registry options, but in the meantime, we need to collect data for the purpose of helping to assess the feasibility of clinical trial sites. This is a reminder that 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.

Notices

Dates for your Diary

The Life You're Given Film 2nd Screening - evening screening, date tbc

APPWS Conference in-person registration closing - August 15th

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

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

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

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