

June 2022 Newsletter

Awareness Month of May

Thank you to everyone who helped to share awareness of PWS by 'going orange', ordering ribbons, wristbands and T-shirts, or by sharing social media awareness posts. If you follow our Facebook page, you may have seen videos from the



3rd day of the last Asia Pacific Conference being shared during the month. These videos all featured individuals and families from Aotearoa sharing aspects of their lives. If you missed these, you can find and share them here on [Facebook](#) or via our [YouTube channel](#).



At the end of the month, we were pleased to announce the availability of some new awareness resources. These pamphlets are easy to distribute to large groups of people and contain useful and need-to-know information for different audiences - 'Whānau, Friends & Community', 'Healthcare Providers' and 'Peers & Housemates'. More coming soon!



These resources are ideal for providing information in one brief publication. Multiple copies can be posted out within New Zealand on request. To [view and order copies](#), please use the order form on our publications and resources page.

Pae Ora Health Reform and Pharmac Review



Some good news from the team at Rare Disorders New Zealand! In a press conference on the long awaited Pharmac Review Final Report, the Health Minister announced that the Government has accepted the review panel's recommendation to 'develop a strategy that will lead to better, more timely services and more equitable support and outcomes for people and whānau with rare disorders'.

The Pharmac Review report recognises the lack of equity in Pharmac's decision making processes and how this affects rare disorder groups. It also recognises the lack of a coordinated approach to rare disorders and recommends a cross-agency approach is needed to address the challenges faced and that this should be led by the Ministry of Health. Rare Disorders NZ is hoping to be able to liaise with health officials in developing a Rare Disorders Strategy as part of the Pae Ora Bill (Healthy Futures Bill). It is important that pressure on the Government is maintained to ensure that a strategy is developed that reflects our community needs.

Unfortunately, funding was taken out of scope for the Pharmac Review Panel. Whilst we look forward to being able to apply for new medications in the future with greater transparency and have our requests assessed equitably, Pharmac still needs a major boost in funding in order to bring New Zealand up to an average level of funding for medicines. In the recent Budget, Pharmac received a boost of \$191 million over two years, but at least \$300 million more per year is needed for Pharmac to bring funding to an average level compared to other OECD countries.

We're calling for

Fair
FOR RARE

Are you with us?
www.raredisorders.org.nz

What can you do?

Arranging a visit with your local MP is a good way to bring attention to important issues which may include Education, Health etc. You will probably be asked what you want to discuss, but your MP has to make a time to meet with you if you request a visit. If you would like some resources to take along with you, RDNZ have some packs available.

Listening to Voices of people living with PWS around the World

This is a **final reminder** about the international study we are participating in by Kamila Lipiec and Kate Woodcock at the University of Birmingham, UK. This is the first study surveying people with PWS in order to capture their voice. It aims to understand how people with PWS feel they fit into society and what is important to them.

We are now one of just a few countries who still have less than 10 participants and we would love to have stronger participation from New Zealand. Kamila and the research team really need at least 10 surveys per country to be able to report findings at conference. The results will provide us with greater insight and will help to inform how we support people with PWS moving forward.

Individuals with PWS aged 16 years or older are invited to participate by completing an online survey, asking for short written answers that can usually be completed within 30 mins. The survey has 'easy read' support and caregivers can support with writing down answers, as long as the answers come from the person living with PWS.

Please [contact us](#) if you would like us to resend study link to you.

Board Member Vacancy

We are always keen to hear from members who have an interest in becoming more involved in the work of our organisation. If becoming a Board Member is something you might be considering, please get in touch with our CEO Charlotte Roos to ask any questions and discuss further: ceo@pws.org.nz.

Special Olympics Achievements

Well done to Karl and Sonia from Blenheim for prizegiving achievements at the Marlborough Special Olympics swimming ribbon day. (LEFT: Sonia with the ladies swim team. RIGHT: Sonia and Karl.)



Data Confirms Association between High-Need Education Funding and School Suspension Rates for Autistic Students in New Zealand

A new study found that high-need education funding among autistic students was associated with reduced odds of suspension. [This data](#) confirms what we know already when many children with PWS also experience suspensions and struggle through school without high-needs learning support (ORS funding.) Due to insufficient increases in the ORS fund over the years and the restrictive criteria which don't take account of broad, complex needs, an increasing number of children with PWS are solely reliant on funding which only supports their health needs - a fund which is often reduced as children move through the education system. "Suspensions were experienced by 57 autistic students (2.0%) with high-need funding and 447 autistic students (6.5%) without high-need funding."

Highlighting useful Resources...

We'd like to bring 2 new resources to your attention:

[SOCIAL SCRIPTS](#) - Interaction, Australia have produced fully adaptable social scripts written for many situations, including: going to a party, grocery shopping, social events, feeling angry.... Follow [this link](#) to browse and download.

[TRANSITION WEBSITE](#) - [Future Ready](#) is a new transition website which contains information and resources, as well as listing providers in your area for: employment, further education, accommodation, sport and recreation, programmes, travel, support groups, and much more.

Amplify U

The new Ministry for Disabled People is due to start 1st July 2022. It aims to lead a partnership between the disability community and government, and to help drive ongoing transformation of the disability system in line with the Enabling Good Lives (EGL) approach.



The Ministry of Social Development is tasked with establishing and hosting the new agency, which will ultimately be autonomous from MSD, once established. MSD has set up a dedicated Establishment Unit to support its establishment, and the transition of MoH functions. You can stay up to date and add your voice to discussions through online engagement tool, [AmplifyU](#), a platform for two-way engagement managed by disabled people for disabled people. A place to share thoughts and engage with the community.

Notices / Events

Dates for your Diary

Zoom Chat for Tweens and Teens - Saturday 11th June, 4pm
Virtual Social Evening for Parents of 0 - 5 Years - Sun 19th June, 7.30pm
Zoom Chat for Adults with PWS - Saturday 2nd July, 4pm
Virtual Social Evening for Parents of Teens/Adults - Sun 31st July, 7.30pm
Transition Expo 2022, Auckland - Wednesday 7th September 2022
PWSA(NZ) Young Families Weekend - Sat 17th - Sun 18th Sept 2022, Wellington
PWSA(NZ) Family Camp - 10th-12th March 2023

Planning for Adulthood

Weds 27th July 12-3pm, Weds 17th August 6.30-9.30pm, Weds 21st Sept 11.30-2.30pm, Mon 17th Oct 6.30-9.30pm, Mon 21st November 11.30-2.30pm

Hosted by Disability Connect, a presentation by Nan Jensen (Barrister and Solicitor) from Quinlaw. This seminar covers the legal framework around disability and disability rights. Click here for [more information and to book \(RSVP essential\)](#)>

Annual Transition Expo 2022

2nd PPT date: Weds Sept 7th, 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.