



December Newsletter



and a Happy New Year!

It has been another difficult year for many, especially for those affected by extended lockdowns. Many events were cancelled this year, including our Young Families Weekend, which can often be additionally challenging for our members with PWS.

However, we can reflect on some positives. We were able to hold our Tweens and Teens Weekend earlier in the year, Cindy was able to run several in-person PWS training workshops and the first, virtually-held Asia Pacific PWS Conference was very successful. Some of our PWSA members helped to produce fantastically insightful videos for the 3rd day of the conference which we will be sharing with you all, especially around Rare Disease Day and PWS Awareness Month next year. These have inspired us to produce more videos in the future and we hope to be able to work with our Adults with PWS Leadership Group in building video resources to use as part of our PWS training material.

We also look back on a year in which major changes to our health and disability systems have been initiated. A new Ministry for Disabled People is being established, the Enabling Good Lives approach to disability support services is being launched nationally, plans are being developed to completely reform of our health system and an independent review of Pharmac is underway.

Earlier this month, we received a copy of the Pharmac Review Panel's Interim Report which has given us hope that the issues and concerns raised by the PWSA and other rare disorder groups will be acted upon. The contents of this damning report are of no surprise, with references to lack of equity in decision making, inequity for rare disorders, non-utilisation of relevant expertise, lack of transparency, slow processes, an excessive focus on saving money and the insufficient medicines budget received. We hope that the full report will propose solutions that result in action from Pharmac and an appropriate Government response. Click here to read our [submission](#) and the [interim report](#).

We also recently submitted feedback to Parliament on the Pae Ora Bill. This Bill outlines the core changes planned for our health system, which include the disestablishment of DHBs and the establishment of Health New Zealand, the Māori Health Authority, and specific health strategies for hauora Māori, Pacific health, and the health of disabled people. Our [submission](#) sought acknowledgement that the rare disorder population are a significant population group that have been overlooked in this Bill. We requested that a health strategy for rare disorders be added in order for the Bill to align with its purpose of improving the health of all New Zealanders and achieving equity. We also did not support clauses which exclude Pharmac from the principles in this Bill surrounding equity and engagement with population groups. We asked that equitable performance be expected from Pharmac and that legislation be amended to reflect issues raised in the recently published Pharmac Review Interim Report.

PWSA Family Camp: 11th - 13th March 2022

A reminder that Family Camp 2022 registration is now open and we would appreciate your registrations as soon as possible please. Our camps are open to people with PWS of all ages to attend with their family or a support worker. Please see our [event page](#) for further details and [online registration](#). Registrations are open until JANUARY 17TH.

Getting Ready for the 2022 School Year



Prader-Willi Syndrome Association NZ



Teachers' Pack



If you would like to order packs for your child's new teacher, syndicate or school, please send us an email or use our [resource order form](#). Packs will be sent out from mid-January to be received before the start of the new school year.

An online version of our packs can be downloaded from our [resources page](#).

We are also able to offer school training when needed (available via Zoom) - please see [Training Workshop 4](#) for details. We also offer advocacy services which include providing support with funding applications, letters of appeal, or providing individual advocacy services as required.

Seasonal Tips for the Holiday Season

Christmas can be a tricky time for people with PWS and their families due to changes in routine, raised expectations and increased anxiety.

You can find some useful [seasonal tips](#) for sharing in our brand-new blog.

Our members are also welcome to offer contributions to our blog - a place for notes, musings, issues and stories related to Prader-Willi syndrome.



Vacancy: Treasurer

We have a volunteer vacancy on our Board for a Treasurer. If you, or someone you know, would be interested in this role, please get in touch with Charlotte Roos: ceo@pws.org.nz

Save Dekken's Gym! Christchurch Gym Facing Closure

Young Dekken has PWS and has been making huge progress since training with Joanne Fahey at [I Got You Fitness Ltd](#) in Christchurch. Unfortunately, Joanne's business is facing closure and Dekken's mum, Rachelle, is devastated at the thought of not being able to continue building on the breakthroughs since his double hip and femur surgery last year. They would love your support - if you live in Christchurch, please consider supporting this business and / or share details with others who may have an interest in working with a personal trainer.

Click here to [read the Stuff article](#) about Dekken and I Got You Fitness.

My Workbridge - New Website for Jobseekers

Workbridge has launched an initiative to help disabled Kiwis looking for work - a website called My Workbridge. My Workbridge advertises jobs with supportive employers, provides tools that help with producing a CV, helps users prepare for interviews, and provides information about accessibility. [Read more about it here >](#) Click here for [My Workbridge >](#)

Donation Matching Offer at FPWR

The Foundation for Prader-Willi Research have their final matching offer for the year. If you would like to donate directly to FPWR before December 31st, your donation will be doubled. The PWSA have just transferred funds from our Givealittle page which collects funds for research, plus other funds donated to us for research. The sum of \$2383.05 NZD will now become \$4,766.10 !!

New UN Resolution Adopted for Rare Disorders!

The United Nations General Assembly has just passed the first-ever resolution for people living with rare disorders, "[Addressing the Challenges of Persons Living with a Rare Disease and their Families](#)". This is a key step towards a brighter future, providing visibility for the rare disease community around the world. This landmark achievement is thanks to the tireless advocacy of international and national rare disease groups from over 100 countries.

The resolution addresses the specific challenges faced by our community, including ensuring access to education, promoting access to work opportunities and supporting participation in society.

PLEASE NOTE - NO ZOOM CHATS FOR ADULTS OR TEENS WITH PWS IN JANUARY.

Dates for your Diary

Zoom Chat for Adults with PWS - Saturday 5th February, 4pm

Zoom Chat for Tweens and Teens - Saturday 12th February, 4pm

Virtual Social Evening for Parents of Teens / Adults - Sun 30th Jan 2022, 7.30pm

Virtual Social Evening for Parents of 6 - 12 Years - Sun 27th Feb 2022, 7.30pm

Transition Expo 2022, Auckland - Wednesday 9th March 2022

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

Young Families Weekend - new date Sat 17th - Sun 18th Sept 2022, Wellington

Notices / Events

Education - Disability and Your Child

Feb 14th, 24th, March 7th, 14th

by Parent to Parent, funded by Care Matters

Informative and free workshops will lead you through the IEP process, how to have productive IEP meetings, how to foster inclusion in the classroom, and the types of funding available to you.

14 February: 10.30am - Zoom

24 February: 7:00pm - Zoom

7 March: 10.30am - Zoom

14 March: 10.30am - Zoom or at 2-12 Commerce Street, Kaitia

REGISTER HERE: www.parenttoparentnz.formstack.com/forms/workshop_registration

More info here: www.parent2parent.org.nz/calendar

Annual Transition Expo 2022

Postponement date: March 9th, 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.