



November Newsletter

APPWS Conference Review

Thank you to everyone who participated in APPWS2021. We hope that you were all able to further your knowledge by attending and found it to be a positive experience. The conference organising committee have received lots of positive feedback, which was reassuring to hear



with this being our first conference held virtually. We had a good number of registrations from families in New Zealand, but also from those in the residential care sector, and a few professionals from the health sector. This provides the PWSA(NZ) with positive assurance to organise further virtual events of this kind. [Click here to read more >](#)

PWSA Family Camp: 11th - 13th March 2022

If you haven't responded to our question about holding camp in 2022 or postponing, this is a friendly reminder to send us a message to let us know your preference. Please submit all responses **by December 6th**. Please click here to respond: jo.davies@pws.org.nz



Attitude: Bradley & Tri Rugby

If you watch Attitude on Sunday mornings, you may have seen an episode featuring PWSA member and rugby captain, Bradley Holt. Bradley's dedication to the sport and his team is inspiring, and he also manages to add some PWS awareness during this heartwarming episode about Tri Rugby in Christchurch. Ka pai Bradley!

This is a must-see episode which you can view using the following link:

<https://attitudelive.com/pla.../my-perfect-family-tri-rugby/>

PWS and Rare Disorder Advocacy

The PWSA recently submitted feedback to Stats NZ on the content of the 2023 Disability Survey. It will have been 10 years since the last Disability Survey in 2013 and it is important to ensure pertinent data is collected from the PWS and rare disorder communities as Governments and other organisations use this data to understand the needs of disabled people and plan services for them. You can view all PWSA submissions on the [News page](#) of our website.

The PWSA also recently endorsed an [open letter](#) by RDNZ, calling on the Government to provide accelerated funding for medicines to keep those with underlying medical conditions and compromised immune systems safe and out of hospital during the spread of COVID-19 in our communities. We were very happy to support this.

Voice of Rare Disorders Survey

If you haven't completed this survey for RDNZ, we strongly encourage you to please consider doing so **by December 1st**. Comprehensive rare disorder data will be gathered to create a clear picture of living with a rare disorder in 2021 and establish a strong collective voice, which can be used to advocate directly with the Minister of Health, health officials, Pharmac and MPs, amongst others. RDNZ are an extremely hard-working organisation, focused on improving access to treatments and services for their collective. They advocate tirelessly on behalf of the collective organisations, informing and educating stakeholders and policy makers, and continuing to call for a National Rare Disorder Framework. Click to [read more about the survey](#). CLICK TO [TAKE PART IN THE SURVEY >](#)

Pae Ora (Healthy Futures) Bill - Health System Reforms

As you will be aware, core reforms are planned for our Health System. This restructure includes the formal, permanent, establishment of Health New Zealand and the Māori Health Authority. The [Pae Ora \(Healthy Futures\) Bill](#) has been introduced to Parliament and submissions are now being accepted, but there is a very short timeframe with submissions closing **December 9th**. The PWSA will be making a submission on behalf of members, with a focus on: referencing rare disorders within legislation, requesting a specific health strategy or framework for rare disorders, obtaining equitable assessment of treatment needs, and on ensuring an unfragmented, cohesive service for complex disorders that is equally accessible to all and not dependent on where you live. If you would like to make your own submission, it can be as short as 1 or 2 sentences and may simply take the form of a personal experience that highlights a needed change. Information on making a submission to this bill can be found on the [Parliament website](#).



Medicines Update - Carbetocin

Unfortunately, after much anticipation and excitement surrounding the FDA priority review of clinical data from Levo Therapeutics' CARE-PWS phase 3 trial of LV-101 (intranasal carbetocin), the FDA's Psychopharmacologic Drugs Advisory Committee voted almost unanimously

against approval. This was very disappointing for the international PWS community, with the crux of the decision appearing to come down to how the FDA framed the question -

whether there was 'substantial evidence' of efficacy rather than asking if there was moderate evidence, which may have resulted in a different outcome. The decision was made despite compelling and emotional testimonies from families and experts involved in the trial. The final decision by the FDA is due by the end of the year, but the FDA is not expected to rule against their advisory committee.

At lower dose, carbetocin showed significant benefits for one measure of hyperphagia and with its promising safety profiles, it has a high ratio of benefit-to-risk for the PWS community. With LV-101 showing such promise for a community where there is a huge unmet treatment need, the FPWR and PWSA USA have vowed to continue fighting for the approval of carbetocin, and Levo Therapeutics will continue to work with the FDA on this. We will be happy to support their efforts in any way we can so that the potential of this treatment can become available to the wider PWS community.

Transformative Change to Disability System Announced

This announcement was long awaited good news. The key points announced were:

- The establishment of a Ministry for Disabled People to lead ongoing transformation of the broader disability system.
- The implementation of the Enabling Good Lives approach to Disability Support Services on a national scale.
- The introduction of The Accessibility for New Zealanders Bill – stand-alone legislation to make Aotearoa more accessible.
- The establishment of a new Accessibility Governance Board.

Announcement excerpts from the Ministry of Health:

" The new Ministry for Disabled People will deliver support and drive better outcomes for all disabled people, embedding a 'whole-of-life, whole-of-family / whānau' approach to disability.

Historically, disability support issues have been treated solely as health issues. They are not. Disability issues and opportunities span across social and economic areas and for the 24% of New Zealanders who identify as having a disability, it is important that we acknowledge this.

Once established, the Ministry will be a dedicated and autonomous agency, which will:

- *Drive better outcomes for all disabled people,*
- *Lead cross-government strategic disability policy,*
- *Deliver and transform Disability Support Services, and*
- *Progress work on Disability System Transformation.*
- *Provide leadership across Government and the public service to ensure we can deliver on these expectations. It also underlines our Government's commitment to ensuring change is lasting and future-focused.*

The principles of Enabling Good Lives were developed by a group from the disability sector and the implementation of EGL is the latest step on a journey that began in 2011, when a group from the disability community presented its vision and principles to Government.

EGL is an approach and system that works, as we've seen with the pilot projects for the transformation of Disability Support Services in Christchurch, Waikato and Mid Central regions.

We know, however, that transformation will take time, and take a fundamental re-think of how the disability system can better support the goals and ambitions of disabled people. It requires looking at the full range of mechanisms across the broader government system, examining how they can be improved and harmonised to better support disabled people. The disabled community's voices will be embedded at all levels of decision-making, from the formation and running of the Ministry to the implementation of accessibility legislation. For a start, while currently we are referring to a 'Ministry for Disabled People', we will collaborate with the disability community to identify an appropriate name.

Given the scale and scope of the new agency, a dedicated Transition and Establishment Team has been set up within MSD to support the transition of functions from MSD and MOH to a new Ministry. The Unit will build on insights from the establishment of new Ministries, such as Oranga Tamariki and the Ministry of Housing and Urban Development. A key focus will be ensuring disabled people continue to receive support over the transition."

Once the details and impact of planned system change become a little clearer and roll-out becomes more imminent, we intend to hold some workshops to help explain details, answer questions, and to discuss how to obtain the best outcomes from the new system.

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

Dates for your Diary

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

Zoom Chat for Tweens and Teens - Saturday 11th December, 4pm

Virtual Social Evening for Parents of 0-5 years - Sun 12th December, 7.30pm
(brought forward due to Christmas)

Virtual Social Evening for Parents of Teens / Adults - Sun 30th Jan 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

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.