



May Newsletter

PWS Awareness Month

May is PWS Awareness Month and, as usual, we have been sharing daily awareness information on [Facebook](#), which we hope you will view and share across your own networks. We have been following weekly [themes](#) - week 1 was talking about 'what is PWS' and diagnosis, week 2 was talking about hyperphagia and diet, week 3 has been talking about management, and next week we will focus on support and sharing '**then and now**' stories. We would love to hear from parents or people with PWS who would be happy to share their story. It can just be a picture or two and a couple of sentences, or a longer story, or even a video - totally up to you! Please send these to jo.davies@pws.org.nz or send directly to our Facebook page or to Messenger.

PWS Awareness Day - Friday 29th May

Thank you to those who have ordered ribbons, wristbands, T-shirts and posters. Friday is the day when people across the world will be wearing orange to help create awareness for Prader-Willi syndrome. Please join the [PWS Awareness Day Facebook event](#) and send in your 'orange' pics!

You might want to get involved in PWS Day by creating some art work you can share. This might be a poster, a creation on the beach, some chalk on the footpath or fence... We look forward to sharing any [#artfromtheheart](#) creations!

Tori & Tyson's Ditch your Lunch Event

Congratulations to Tyson and his mum, Tori, who have organised a 'Ditch your Lunch' event for PWS Awareness Month. Tyson has 78 people participating so far, to acknowledge the hunger that individuals with PWS are living with every day. All support is appreciated and optional donations of the cost of a lunch are being collected for PWS

research: www.givealittle.co.nz/org/pwsresearch.

Please let us know if you would like to be put in touch with Tyson and Tori's event to show your support.



Other PWSA News

Zoom!

During lockdown we held some Zoom meetings for both teens and adults with PWS and there is interest in continuing these, so they will be back! We plan to set up a regular schedule of meetings and there have been requests for parent meetings too. We think parents may prefer meetings which are child age group based - please let us know if you have any additional thoughts. We are currently looking at video conferencing options that would provide greater flexibility and will let you know as soon as we are up and running!

IPWSO Conference Report

We are pleased to forward more information from the 2019 IPWSO Conference in Cuba from New Zealand attendees. Hayley Arnott has a 4 year old daughter with PWS and has written the following useful [summary](#). In case you missed it, you can also view an [interview](#) with Dr Jennifer Miller by Dane and Julia Fuller.



Choice and Control: restrictive practices in the care of people with PWS

IPWSO would like to invite you to take part in a survey they are running with the University of Cambridge to find out more about people's views on the best way to support healthy lifestyles for people with Prader-Willi syndrome, whilst ensuring their rights are respected.

If you would like to take part, please [click here](#) to read the participant information, complete the online consent form and take the survey.

If you know other people who would be interested in taking part in this research, please forward the link to them.

The results of this research will be used to help develop a set of guidelines.

If you would like to see the first draft of the guidelines and have the opportunity to take part in a consultation exercise, please drop a line with your name and email address to the project mailbox: research@ipwso.org

Budget News

Rare Disorders NZ is disappointed with the \$10m boost as part of a \$160m package to PHARMAC over four years. "In real terms this amount is a drop in the ocean of unmet need for adequate medicine funding in New Zealand, and will not help people living with a rare disorder. The \$10 million increase for the next financial year will not even be enough to enable the status quo, considering the extra costs due to the current covid-19 crisis."

"We ask for transparency of the investment that would be required for PHARMAC to ensure equitable access of modern medicines in New Zealand..." Click to read their full [media statement](#).

There is some good news for those applying to or receiving the School High Health Needs Fund (SHHNF).

The \$79.7 million [Learning Support package](#) will provide additional funding for the SHHNF. Since 2014 the number of students supported through the SHHNF has grown by an average of 16.3 per cent each year.

Dates for your Diary

PWS Awareness Day - Friday 29th May 2020

Regional Notices / Events

Planning for Adulthood - The Legal Framework around Disability and Disability Rights

Weds 27th May - ONLINE VIA ZOOM - 6.30pm-9.30pm

- The long term welfare of your young person with a disability when you die – who will support them to make decisions about their personal care and welfare? And who will understand their needs and make decisions about their personal and physical welfare on their behalf if they are unable to do so?
- The difference between welfare guardianship, power of attorney, property management and how a Trust may be useful for managing property.
- The relevance of a Will and Letter of Wishes.
- Managing and protecting assets or income of your young disabled person.
- Family trusts or sole beneficiary trusts for management of assets.

There is a charge of \$20 per family and \$50 per professional working in the disability sector. RSVP is essential: 09 636 0351 or admin@disabilityconnect.org.nz . Click here for [more information and dates](#).

Regional events and workshops may be cancelled, postponed or 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.

