



May Newsletter

We are nearing the end of **PWS Awareness Month**! Thank you to everyone who has ordered awareness resources and we hope these have been received. Next week, it is **PWS Awareness Day** on **Friday 28th May** - the PWS community around the world will be wearing orange and sharing pictures, raising awareness and hope. We would love to share any pictures you send us!

We will be going orange for PWS Day with a group of our tweens and teens at our weekend event in Wellington. We have 12 teens attending with a parent and we are looking forward to seeing everyone. Final programme details will be with those attending very soon!

Canterbury Events

Families in the Christchurch area recently got together for a pleasant sunny afternoon at Halswell Domain.



This was followed by a day out for a group of adults with PWS from Christchurch who travelled down to Ashburton to reconnect with friends living a bit further afield. Cindy enjoyed catching up with everyone for a lovely day out.



Flu and Covid-19 Vaccinations

PWS is classified as an underlying health condition and disability which is considered a priority for Covid-19 vaccinations, alongside vaccinations for residential care staff and carers of disabled persons. Vaccinations for PWS are due to be offered in [phase 3](#) - invitations from your local DHB should be sent out late May.

As usual, the [annual flu vaccine](#) is available for people with PWS, but this year it is important to consider the timing with Covid-19 vaccinations, as they need to be given at least 2 weeks apart. Therefore, if the flu vaccine is given first, the first Covid-19 vaccination can be given from 2 weeks later, but if a Covid-19 injection is given first, the flu vaccination cannot be given for at least 5 weeks following the 2nd Covid-19 injection.



New Zoom Meeting Time for Adults with PWS

Zoom meetings for adults with PWS will now take place on the 1st Tuesday of each month at 4pm. First meeting next week - **Tuesday 1st June, 4pm!** The link and password remain the same, but we will send out a reminder email. Links and details can always be found here on our [events page](#). We hope to see you there!

Revised PWS Training Workshops

We have recently revised the PWS training we are able to offer to support providers and schools. This is mainly because we now have an additional option of online training via Zoom which we began offering during the Covid-19 restrictions, but has since proven to be a successful and often more flexible way of delivering training.

Please see our [Training Courses page](#) for full details of the different workshops available, new pricing details and a booking request form. Please contact us with any questions.

IPWSO is Celebrating 30 Years!

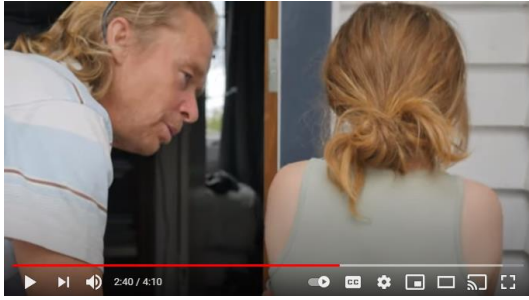
The International PWS Organisation was formed in May 1991 when delegates from 25 countries gathered in the Netherlands for the first international PWS conference. To celebrate 30 years, IPWSO has produced a [series of films](#) featuring those who were involved at the beginning. IPWSO also aim to provide 30 free diagnostic tests for PWS this year in countries where this is not available. Please click here if you wish [to donate >](#)

Linda Thornton established our Association in 1989 and served as National Director until 2011, but Linda was also a founding board member of IPWSO and went on to work in IPWSO's office until retiring in 2020. In one of IPWSO's films to mark 30 years, Linda talks about those early years and the importance of continuing IPWSO's work into the future. [Watch here >](#)



Thank you to Dane Fuller

We would like to express our gratitude to Dane Fuller at [Hugable Kids](#), Sarah Colchord and Monty Betham of Chooice, and all buyers of Hugable Lions for their kind support of the Prader-Willi Syndrome (NZ) community. Dane Fuller raised a total of \$1285, in addition to lots of PWS awareness. The Lions have been a great addition in many households.



Vagabond Family Video

Paul, Emma, Lola and Isla (aka The Vagabond Family) have been travelling around New Zealand in their bus [raising PWS Awareness](#) and now they have produced a short video to bring attention to the lack of support available for pupils with PWS in the education system. Please [watch and share](#) to help their cause.

Lie Down for Life Campaign

On May 12th, hundreds of Kiwis ['lay down for life'](#) at locations around the country to campaign for an increase to the Government funding of Pharmac. In this week's budget, there has been an increase, but it falls well short of the funds needed for all the new medications assessed as a high priority for funding.



A petition was presented to Parliament with over 100,000 signatures, but there is still time to sign this - [it closes in 9 days!](#) Please go to [sign4life.nz](#) and share.

When new medications become available for PWS, they are likely to be added to the long list of medicines that cannot be funded. Unfortunately, it is also rare disorder groups that often miss out on funding due to assessment criteria which prioritise the funding of drugs that treat larger groups of New Zealanders. We need both an increase in Government funding and a thorough review of Pharmac's processes, with the establishment of a specific assessment pathway for rare disorder medicines (as requested in Rare Disorders NZ's proposal for a National Rare Disorder Framework.)

National Rare Disorder Framework Update

Following the petition to Parliament by RDNZ, the Petitions Committee invited RDNZ to provide a written submission on their petition for a National Rare Disorder Framework, which will be provided to the Health Select Committee to help its consideration of this. Click here if you wish to read RDNZ's [full submission](#).

What can you do?

1. If you haven't already, please sign and share Patient Voice Aotearoa's [Parliamentary petition](#) BEFORE 31st MAY. This can also be found using the link [sign4life.nz](#)
2. Share key messages across your social networks. Visit: [weareworthit.nz](#)



PWS Awareness Month - Donation Matching

If you or somebody you know were planning to donate to PWS research that will lead to new treatments for PWS, the Foundation for Prader-Willi Research have a donation matching offer until May 31st. All donations will be matched up to \$100,000! Click here to find out [how to donate](#).

Research and Medicines Update - DCCR

There has been lots of talk about DCCR (Diazoxide Choline Controlled Release) in the International PWS Community lately because PWSA(USA) and FPWR have been advocating for approval from the FDA (the drug approval agency in the USA).

DCCR is thought to affect leptin pathways by opening KATP channels and also to improve GABA signalling. (Leptin is a hormone that helps to regulate energy balance by inhibiting hunger and its pathway is thought to be disrupted in PWS.) Initial [trial results](#) showed a promising improvement in hyperphagia, decreases in body fat and improvements in aggressive behaviours, so Soleno Therapeutics launched DCCR into a phase 3 clinical development program (DESTINY PWS).

However, they believed these trial results were negatively skewed by the impact of Covid-19, so when seeking a New Drug Application, Soleno submitted additional analyses which revealed these differences in results and hoped that data generated pre-pandemic would be sufficient. Following review of this data, the FDA requested an additional controlled clinical trial to support an NDA submission for DCCR in PWS. This ongoing extension study, named C602, is underway.

Alongside Soleno, PWSA(USA) and FPWR launched a campaign requesting that the FDA reconsider the need for another trial and avoid delaying access to this treatment. They stated that the impact of Covid-19 disruption influenced DESTINY PWS and requested that robust pre-pandemic findings were not dismissed. They have been collecting and compiling the experiences of patients and caregivers during the completed DESTINY PWS clinical trial and in the ongoing C602 open-label study. This information was sent together with a letter on DCCR to the FDA .

Dr Jennifer Miller, Prof of Paediatric Endocrinology and Principal Investigator, says "DCCR therapy results in meaningful improvements in hyperphagia in severe patients, as well as various other positive impacts in behaviors and body composition, and if approved, could offer a safe and effective treatment to PWS patients struggling to manage their symptoms. My experience with DCCR in the largest cohort of patients in this study is consistent with the overall effects seen in DESTINY PWS,"

Soleno have announced they will be hosting a webinar highlighting DCCR for the treatment of PWS at the 23rd European Congress of Endocrinology 2021, on Monday, May 24. It will feature presentations by Dr Jennifer Miller, Dr Theresa Strong and PWS key opinion leaders from France and the UK.

Dates for your Diary

Tweens and Teens Weekend - May 28th - 30th, Wellington

Zoom Chat for Adults with PWS - Tuesday 1st June, 4pm

Zoom Chat for Tweens and Teens - Saturday 12th June, 2pm

Virtual Social Evening for Parents of 0-5 year olds - Sun 27th June, 7.30pm

Transition Expo 2021, Auckland - 8th September

Young Families Weekend - September 2021, date TBC, Wellington

The 5th Asia Pacific PWS Conference - Fri 29th - Sun 31st October 2021

Notices / Events

A Good Life & Partnering with your NASC

May 25th - Rotorua, June 22 & 24 - Dunedin & Invercargill

December 8th - Auckland 'Tips for Positive Engagement with Taikura Trust'

by Imagine Better

This free workshop will provide the opportunity to explore what makes up a good life and what it could look like for you. Local Area Coordinators recognise that having access to disability support that is simple to use and is flexible is a key part of achieving a good life for some people. Gaining access to disability supports means having a relationship with the Needs Assessment and Service Coordination (NASC) service in your area.

Click here for Rotorua, Dunedin, Invercargill: [further details and registration >](#)

Click here for Auckland: [further details and RSVP >](#)

Planning for Adulthood: The Legal Framework

June 2nd and 23rd - Auckland venues

by Disability Connect

Formerly known as Trust and Welfare Guardianship seminar. RSVP essential.

Click here for [further details and booking >](#)

Annual Transition Expo 2021

September 8th, 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.