



November Newsletter



Leadership and Social Weekend for Adults with PWS

After originally being postponed, we were very pleased that our adults weekend was able to take place in October. This was our first event just for adults and we think it was a great success! Thank you to all those who attended and those who came to support; we hope you all had a fantastic time!

The weekend had a focus on advocacy and leadership, but also included lots of games and social activities - click here to [read news](#) about what they got up to and to view photos. One of the successful outcomes of the weekend was that the group recorded their ideas about what others should know about PWS. We asked them to do this to help with putting together new resources for flatmates, classmates, or peers, and we will compile these thoughts and share new resources with you soon. In the meantime, you can read their collective thoughts here: [What Others Need to Know](#). You can read more on the web page for the [Adults with PWS Leadership Group](#).



Caralluma Fimbriata Trial Opportunity

A reminder to [email us](#) if you wish to register interest in a possible, future CFE trial that can be extended to include NZ participants if there is significant interest. Thank you to those who have got in touch already. Some families in NZ participated in Joanne Griggs' [2015 study](#) and Joanne has recently provided an [update](#) on her CFE research and reports on the continued success of CFE supplementation for her daughter, Mia.

"We have determined CFE to significantly improve appetite behaviours in children and adolescents after 4-weeks treatment, compared to placebo, recorded by parent/carers. The highest response was at the recommended adult dose (1000mg/d CFE) in average weight participants."

End of Year Regional Events

We hope to hold some regional days out before the end of the year - these will be held around our main centres or anywhere where a group of local families can meet. We are looking for volunteers to help coordinate an event in either Auckland, Christchurch or Nelson. We can advertise the event for you, manage RSVPs and provide some funding toward it - all you need to do is suggest a venue, suitable date and be a point of contact on the day. Suggestions might be a trip to a zoo, bowling, a family BBQ picnic or meeting at local pools? If you can help, please contact jo.davies@pws.org.nz



The Vagabond Family Update

Paul, Emma, Lola and Isla have set off on their bus trip around New Zealand - they are 'On the Move for PWS!' Please look out for them on their travels or contact them via their [website](#) if you would like to ask a question or catch up. You will be able to follow their progress on their [blog](#) or via [instagram](#).

Zoom Chat & Virtual Social Evenings - reminder of days / times

Zoom Chat is a monthly meeting for people with PWS. These take place on the **2nd Saturday** of each month, at 2pm for tweens / teens and 3.30pm for adults with PWS.

Virtual Social Evenings are also monthly, but for parents with children of different ages each month. There will be a virtual social evening every 3 months for your child's age: 0-5yrs, 6-12yrs, and teens / adults. These meetings now take place on the **last Sunday** of each month at 7.30pm. (This month is for parents of 6-12yrs).

There is also a social evening specifically for dads, which is held every 3 months on the last Wednesday of a month at 7.30pm (next meeting is Nov 25th).

If you are ever unsure of dates, times and meeting links, these can always be found on our website [events page](#) or in the events section of our [Facebook page](#). If you click 'going' on a Facebook event, you should also receive a Facebook reminder! If you forget the password to access a meeting, just message us and we'll get right back to you!

News from PWS Conferences

The 2020 FPWR PWS research symposium took place in virtual format from Sept. 30th – Oct. 1st. There were 23 speaker presentations and 20 poster sessions sharing inspiring findings toward successful treatments for PWS. Click here to [download the collection of all abstracts](#) featured at this event!

These presentations represent FPWR funded projects and a variety of PWS topics and research findings from genetics and cell biology, to clinical studies, to PWS mental health, and more.



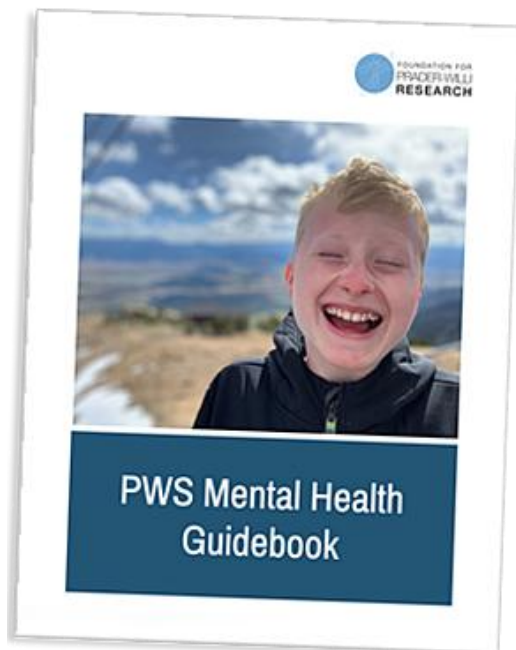
The FPWR family conference was also virtual this year and all the recordings are now available to [watch here](#). Some of the presentations include: Optimal Nutrition, Moving the Barriers for Improved Behaviour (5+), Deconstructing Anxiety in PWS, Improving Social Functioning (5+), and Orthopaedic Challenges.



Useful New PWS Resources

PWS and Sleep Disorders

Narcolepsy and cataplexy, excessive daytime sleepiness, apnoea, and other sleep issues are explored in this recorded webinar. Moderated by Maria Picone, Founder / CEO of TREND Community, with expert panelists from Texas Children's Hospital and Harmony Biosciences, featuring 2 teens with PWS as guest speakers. [Click here to watch >](#)



PWS Mental Health Guidebook

This new, in-depth resource on mental health and PWS was written by Lauren Schwartz Roth, Ph.D., and is based on interviews with family members of individuals with PWS, as well as experts in mental health. To [download the resource](#), scroll down the FPWR web page to where there is a box to insert your email address.

Improving the Well-being of Siblings

Tips for improving the well-being of PWS siblings through debriefing - [read article >](#)
Also, Parent to Parent have produced some new resources for siblings coping with anxiety - [download booklets here >](#)

Survey: 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

PWS Research News: Carbetocin

If you have been following news about oxytocin trials, you would have been very excited to hear the positive interim results of Levo Therapeutics phase 3 Carbetocin trial (CARE-PWS). At the lower dose, significant improvement was observed in hyperphagia, anxiety and distress behaviours. If a new drug application to the FDA in the USA is successful (takes 12-18mths), Carbetocin could soon be one of the first new treatments available for PWS since growth hormone!



Individuals with PWS are believed to be deficient in oxytocin, a hormone associated with social cognition, OCD, anxiety and appetite control, amongst other things. Carbetocin is an oxytocin-like treatment, administered intranasally, which targets only the oxytocin receptor,

reducing impact on other systems, i.e. vasopressin signalling. (Activation of vasopressin receptors could generate aggression.)

Find out more in this Levo Therapeutics [press release](#). On our website, you can also find a summary of [oxytocin / carbetocin research to date](#) >

Dates for your Diary

Zoom Chat for Tweens and Teens - Saturday 14th November 2pm

Zoom Chat for Adults - Saturday 14th November 3.30pm

Virtual Social Evening for Dads - Wednesday 25th November 7.30pm

Virtual Social Evening for Parents, 6-12yr olds - Sunday 29th November 7.30pm

Other News in New Zealand

Fair for Rare NZ Campaign Update

When new treatments, such as Carbetocin, become available for PWS, it will most likely be very difficult to get them funded in NZ. Applications for new medicines by rare disorder groups are not reviewed equitably partly due to lower study participant numbers, fewer studies, and the higher cost of medicines for smaller user groups. We need a rare disorder framework!

Rare Disorders NZ are calling on the government to commit to the development of a National Rare Disorder Framework. Political commitment is needed to recognise the challenges faced by people with rare disorders and to improve healthcare and wellbeing for those affected. One of the [7 strategic priorities](#) identified for a framework is '*Equitable access to modern rare disorder medicines through a specific assessment pathway*'. The PWSA(NZ) is part of RDNZ's collective of over 140 rare disorder groups that they represent and we have endorsed their soon to be published campaign document which will be included in a briefing to the incoming Minister of Health. The campaign is gathering momentum, with the petition to be presented to parliament just after Rare Disease Day, February 28th 2021. Together we are strong! [#FairforRareNZ](#)



What can you do?

1. If you haven't signed and shared the parliamentary petition yet, please click here [to sign](#).
2. Check out the RDNZ [campaign resources](#), including a template for writing to your MP or the Prime Minister.
3. Share this [video](#) across your social media.

Flexibility for Carer Support and IF extended again until Nov 30th

The flexibility for carer support days and IF has been extended again until 30 Nov 2020. This was introduced because families were unable to use their allocation during lockdown. The flexibility allows carer support days to be used for the purchase of sensory items / technology, i.e. headphones etc. It can also be used for any service that helps you have a break or provides a break for the person with a disability. (See this [MOH link](#) for details). Instead of asking a carer to sign a carer support form, you need to attach the purchase receipts, write the total cost and sign for reimbursement. We recommend calling the number on your claim form to check if a purchase will be funded before buying.

Notices / Events

Wellington Transition Expo 2020 - November 7th

10am - 2pm at Kimi Ora School, Lower Hutt

There will be over 30 organisations at this free expo with info on Supported Living, Supported Employment, community activities etc. The organisations include NASC Agencies, WINZ, Total Mobility, Parent2Parent, CCS, LifeUnlimited, Special Olympics, StarJam, law firms, Workmates, Manaaki Trust, Spectrum Care, and more!

WELLINGTON TRANSITION EXPO

What's next after secondary school?



Saturday 7th
November
10am - 2pm

**Kimi Ora School - 100 Walters St,
Naenae, LOWER HUTT**

Employment Opportunities

Disability Connect have provided some useful information and links for those looking for opportunities, from fruit picking to employment agencies. [Click here >](#)

Welfare Guardianship Online Workshop

Thursday 12th November, 10am - 1pm

Presented by Nan Jensen - AbilityWorx, Barrister and Solicitor at QuinLaw. An opportunity to learn about legal structures that will support the future for your disabled family member. Free for registered Parent to Parent families. You need to RSVP to confirm your place by emailing: breanna.turner@parent2parent.org.nz

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.