



July Newsletter

PWSA News

Adults Weekend

We are very pleased to announce the date of our first weekend just for adults with PWS. This will be held in Auckland from **Friday Sept 18th - Sunday Sept 20th**. Please save the date and look out for further information coming to your inbox soon. The weekend will have a focus on advocacy and leadership, but will also include plenty of time for social activities. Follow this link to read a summary of the [recommendations](#) made by the Adults with PWS Leadership Group at our last family camp.

Awareness Month News

Congratulations to Tyson and his mum, Tori, who organised a 'Ditch your Lunch' event for PWS Awareness Month and raised \$385 for PWS research via givealittle:

www.givealittle.co.nz/org/pwsresearch

Also, thank you to those who participated in Awareness Month by wearing orange, sharing posts, stories and information.



If you followed our daily Facebook posts during PWS Awareness Month, you may have read Karen O'Reilly's lockdown musings which were an interesting analogy between everyday life for individuals with PWS and the changes we all experienced to our daily life with the lockdown restrictions imposed upon us. You can read [Karen's musings](#) here.

Coming Soon....

New Facebook Groups

Soon we will be launching new Facebook groups for parents / guardians of children with PWS of different age groups. We intend to keep our existing all-ages group '[NZ Prader-Willi Support Community](#)', but we understand that parents would sometimes prefer to use a group where other members are more likely to be living through similar experiences.

As our New Zealand PWS population is relatively small, we are planning to launch these new groups with PWS Australia as their support systems are not too dissimilar to ours.

Zoom Chat

As mentioned previously, we will soon be starting up regular Zoom meetings. These will be starting later this month and will be run on a monthly basis as below. More information coming to your inbox soon.

[Parents Chat](#) - Friday 6.30pm, every 3 mths (Month 1 - child age 0-5yrs, Month 2 - child age 6-12yrs, Month 3 - child age 13+)

[Dads Chat](#) - Thursday 6.30pm, every 3 mths

[Teens with PWS](#) - Weekend afternoon, monthly

[Adults with PWS](#) - Weekend afternoon, monthly

We will be evaluating how well this works and will make any changes as needed.

New Zealand Behaviour Specialist Conference Presentation

Christina Ford, who is a Behaviour Specialist at Community Connections, presented at the IPWSO Conference in Cuba and has kindly forwarded a copy of her presentation. It is a reflection on the practice tools and techniques used to have conversations in behaviour support and education sessions with a person with PWS, and when there is a requirement to discuss difficult subject matter. Click here [to view >](#)



Caralluma Fimbriata Research

"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."

Dr Joanne Griggs has provided an [update](#) on CFE research and reports on the continued success of CFE supplementation for her daughter, Mia, who has PWS. Some families in NZ participated in Joanne's [2015 study](#) and it is possible there may be a future trial that can be extended to include NZ participants if there is significant interest. Please [email us](#) to register interest.

GHT Research & News

A recently published study will be of interest to families who are keen to start early GH treatment but experience delays due to sleep apnoea concerns. This [study](#) suggests that GH use in infants with PWS does not appear to be related to the development of sleep apnoea. "Obstructive Sleep Apnea in children with PWS appears to develop independently of treatment onset. Treatment may therefore safely be initiated early but should be accompanied by regular sleep analysis."



It has also come to our attention recently that endocrinologists in New Zealand are taking different approaches to initiating treatment, with some doctors slowly increasing the dose to 100% over a few weeks and others doing this over a few months. There also seems to be some differences in the dosage used for calculating the correct dose - this should be 1.0 mg/sqm for infants. International guidelines recommended starting with a daily dose of 0.5 mg/sqm, to minimise any potential side effects, with subsequent increases to full dose, although there is no agreement as to how rapidly this should occur. However, [evidence](#) for efficacy in infants and children is based on trials using the full dose within approximately 1 month of starting treatment.

Covid-19 and PWS Update and Surveys

As far as we know, no individuals with PWS have had COVID-19 in New Zealand, but IPWSO have been collecting data via a [survey](#) over the last couple of months from those who have experienced a COVID-19 infection to better understand how COVID-19 might present in people with PWS, and also to investigate the course and outcomes of the illness. [Early results](#) from this survey have now been made available.

An [FPWR survey](#) is investigating the impact of the pandemic and lockdown on the PWS community, examining changes to behaviour, mental health, education, social activities, and access to therapies and medical care.

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 life styles 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

Dates for your Diary

Weekend for Adults with PWS - Friday 18th September 2020

Other News in New Zealand

Fair for Rare NZ Campaign

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 for those affected to be made a health priority. Click here to read the [7 strategic priorities](#) identified for a framework that will improve healthcare and wellbeing for all people living with a rare disorder.



If you haven't signed and shared the parliamentary petition yet, please click here [to sign](#). It only takes a moment and Rare Disorders NZ would really value our support. [#FairforRareNZ](#)

Flexibility for Carer Support and IF extended until Sept 30th

The flexibility for carer support days and IF has been extended until 30 Sept 2020. This was introduced because families were unable to use their allocation during lockdown, but unfortunately, it was not very well publicised. The flexibility allowed 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.

How you find and use information that helps you

The MSD are working with Tandem Consulting to discover more about how you find and use information that helps you in your role of carer. They're looking for a wide range of carers from different backgrounds and ages. Everyone who is interviewed will receive a gift voucher. Contact Philip at IHC on 0800 442 442 ext 45741 or philip.clarke@ihc.org.nz

Notices / Events

Parents Support Group - Managing Anxiety

Mon 13th July - ONLINE VIA ZOOM - 6.30pm - 8pm

Disability Connect have invited Judy Ng (Registered Psychologist/Behaviour Therapist) to this meeting to deepen understanding of anxiety and discuss strategies that may help manage it. Judy would be happy to discuss any individual circumstances if you wish to submit these prior to the meeting.

Judy has worked in Explore Specialist Advice for 5 years as a clinical supervisor and facilitator for ASD programmes. Judy takes an integrated approach and her holistic approach has helped many people to overcome/manage their anxiety successfully.

Attendance by [registration](#) only - register early as this is a popular topic. Parents are not charged to attend these support groups, however the professionals fee is \$50 each per support group or seminar.

Sibling Anxiety Zoom Workshops

Various dates July - August

Are the siblings of your disabled child experiencing anxiety? Tune in to this workshop to learn how to support these special siblings. Growing up with a brother or sister with a disability comes with its own unique challenges. Feelings of isolation or guilt, low self-esteem and coping with bullying are common complaints. For some children the experience can lead to significant levels of anxiety. This workshop for caregivers will teach you how to recognise anxiety and take you step by step through a range of practical solutions to help support siblings. Numbers are limited so register today!

Click below for more details or call Parent to Parent on 0508 236 236.

[Wellington 3rd July and 7th August 2020 \(2 sessions\)](#)

[Greater Canterbury 24th July 2020 \(2 sessions\)](#)

[Northland 31st July 2020 \(2 sessions\)](#)

[Manawatu 7th August 2020](#)

Transition Expo 2020 - September 2nd

9am - 2pm at The Auckland Netball Centre, 7 Allison Ferguson Drive, St Johns

The Disability Connect annual Transition Expo enables you to explore opportunities and advice from Transition, Vocation, Recreation and Information Providers, Pet Therapy, Dancing, Sports, competitions and much more.

Click here for [more details](#).

Many regional events and workshops are being presented online at the moment. Others may be cancelled or postponed. 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.