



December Newsletter



We would like to wish you all a safe and Happy Christmas. It has been a difficult year for many and it seems so long ago now that we were holding our Family Camp at Lake Taupo near the start of the year. Here's hoping that 2021 will be a much better year for everyone. We will be taking a break now over Christmas and into the New Year, but we can always be contacted via email or by phoning our helpline: 0800 4 PWS HELP.

Regional Summer Events

Parents in Christchurch recently enjoyed a coffee catch up and we would like to encourage more regional events like this, plus days out during the Summer for both families and adults with PWS. Details coming soon about Wellington and Christchurch family days next year. We are still looking for help coordinating events in Auckland and 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, date, and be a point of contact on the day. A family day is usually held at a venue where families plus adults with PWS and Support Workers can meet. This could be a bring a plate BBQ in a park / at local pools / at a beach; meeting at a hired venue such as a community hall or local kindy; or meeting at an animal park, museum, activity venue etc. If you can help, please contact jo.davies@pws.org.nz

IPWSO Health ECHO® Programme

Health ECHO® is a free, online programme developed by IPWSO for health professionals working with people with PWS. Health ECHO is designed to build a PWS knowledge network across the globe based on an "all teach, all learn" methodology.

We have sent details about Health ECHO to New Zealand's paediatric and endocrinology groups and teams, DHBs, Therapy and Child Development Teams etc. You may also wish to forward details to your own health professionals in case details haven't reached them. The programme starts in February 2021 and online registration is now open.

Health ECHO will be of interest to a wide range of professionals including geneticists, endocrinologists, neonatologists, nurses, paediatricians, psychiatrists, psychologists, social workers, physio and occupational therapists, pulmonologists, orthopaedic surgeons, dietitians, speech and language therapist, medical students and professional caregivers.

Sessions will include short and focused presentations by medical experts on PWS, as well as the discussion of anonymised cases presented by participants. There will be 10 sessions lasting 90 mins each and numbers will be restricted to enable maximum participation. Click here for [further information >](#)



Hug-able Fundraising

We would like to thank Dane Fuller for his wonderful Hug-able fundraising initiative. Dane has raised lots of awareness of PWS and funds for PWSA(NZ), which we are all very grateful for. If you would still like to order Jasper the Hungry Lion or the lion cub for Christmas, there is one day remaining - last orders by Weds 9am.

You can learn more about Hugable Kids by following Dane's page [Hug-able](#) and you can click here to [order your lions >](#)

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."

Dates for your Diary

Zoom Chat for Tweens and Teens - Saturday 9th January, 2pm

Zoom Chat for Adults - Saturday 9th January, 3.30pm

Virtual Social Evening for Parents of Teens & Adults - Sun 31st January, 7.30pm

Virtual Social Evening for Dads - Wednesday 24th February, 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. Share the parliamentary petition; 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.
4. Put on your thinking caps for Rare Disease Day! We want to raise lots of awareness about rare diseases and the need for this framework on RDD, Feb 28th 2021.

Flexibility for Carer Support and IF extended again - FEB 28TH

The flexibility for carer support days and IF has been extended again until 28th Feb 2021. 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.

Unbreakable Series 2 are on the hunt for participants

TVNZ's award winning television series Unbreakable is back for a second season and are on the hunt for participants. If you live with a disability and have a big dream or goal that you are working towards and would like to be involved, please get in touch. Send a recent photograph and a brief description of the goal you are working towards to: racheljudkins@storymaker.co.nz. Applicants should be over the age of 18 and be available for filming between February and August 2021: www.tvnz.co.nz/shows/unbreakable

Notices / Events

Employment Opportunities

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

Safe Relationships and Sexuality Workshops 2021

12th February, Auckland

Claire Ryan has more than 10 years' experience in delivering training and workshops on sexuality. She is a firm believer that information is power, and she is passionate about spreading the message that disabled people should have the right to explore and express their gender and sexuality. Topics will include: safety in relationships, sexuality – what it means, intimate support, touch, contraception, legal aspects – consent.

10:00am to 12:00pm - Education Providers

2:00pm to 4:00pm - Open to disabled people, carers and health professionals

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

Managing Anxiety Workshops 2021

20th and 24th February, Auckland

To deepen our understanding of anxiety and discuss strategies that may help manage it. View further information about the specialist presenters and [book here >](#)

Transition Workshops: Life after school: what's next?

April and May 2021, Napier and Nelson

by Imagine Better and NZDSN

Who Should Attend? 13 – 21 year old college students and their family / whānau, educators, Ministry of Education staff, service providers involved in 'transition', employment and day support, other key stakeholders. Free for disabled students and their whānau. [Further information and registration >](#)

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