



February Newsletter

We hope you have all had a great start to the year and are now keeping well amidst the rapid rise in COVID-19 case numbers. Those who had registered for our summer camp are already aware that unfortunately we had to postpone this year's camp due to the omicron outbreak. This was due to the expected fall in attendance numbers once cases began to climb and because of the difficulties some may have faced in being able to travel to camp with the possibility of flight cancellations. We are looking forward to getting back to normality and being able to hold camp on the new dates of **March 10th-12th 2023**. Click here for [registration and flight subsidy details](#). (A reminder that existing registrations have been rolled over to the next camp - no need to register again.)

Antiviral medications for the more vulnerable

PHARMAC have announced a very brief consultation period (closing **5pm Wednesday 2nd March**) on the proposed access criteria for the limited supply of new antiviral medications that have been ordered for treating patients with COVID-19. The proposed criteria would result in many of our more vulnerable members with PWS being excluded from access, should they need them.

It is important to reassure you that data collected so far (by a French [study](#) and a small IPWSO [survey](#)) has shown that PWS itself does not appear to be a risk factor for serious illness with COVID-19, and those infected have experienced more favourable outcomes than expected. The risks may be similar to the general population so it is inevitable that sadly, we are aware of those who have been more severely affected internationally. (If required, information can be found on our website: [Covid-19 and PWS](#).)

Proposed Access Criteria

COVID-19 patients who are immunocompromised would qualify, but it is thought that most people with PWS would have adequate immune responses. For those who are not immunocompromised, patients would have to meet 1 of the following criteria (unvaccinated) / 2 of the following criteria (vaccinated):

- over 65 years
- of Māori or Pacific ethnicity
- have a listed comorbidity

These criteria are concerning as most of our more vulnerable members are highly likely to be vaccinated, yet the prevalence of comorbidities are likely to be high. We expect the

peak of omicron may be flattening by the time these medications are available, but with the rapidly evolving nature of COVID-19 and the possibility of further variants, it is important to send a message of community need, especially as our health system does not keep any substantial rare disorder data and in particular, on the risk factors for specific rare disorder populations. Other countries have the availability of detailed analysis to evidence clear risks. We need to ask for prioritisation based on assessed vulnerability, perhaps a category for multiple comorbidities, or for 'other proven health risks based on patient history' to be an acceptable category .

The PWSA will submit feedback, but we also encourage you to do so if you have concerns. Feedback can include examples of need. Click here to view details of the [consultation](#). Feedback should be emailed to: consult@pharmac.govt.nz

Rare Disease Day 2022 / Fair for Rare NZ Campaign



Are you with us?
www.raredisorders.org.nz

Despite written and oral submissions by many rare disorder groups to the Pae Ora Legislation Committee, the indication is that the Government and Ministry of Health will not establish a National Framework for Rare Disorders, nor will they recognise those with a rare disorder as a population with distinct needs at this time. The Government feels that the Pae Ora health reform will improve things for all people, including those with rare disorders. Without recognition of people with rare disorders as a population group with evidenced needs, how can there be awareness of the common threads and issues within the current system?

On behalf of their collective, Rare Disorders NZ are not giving up. It is only with recognition that we can have improved outcomes. As the Pae Ora Bill is a once-in-a-generation health reform which outlines core changes planned for our health system, Rare Disorders NZ will be insisting that rare disorder groups are consulted during the preparation of health strategies and are included in the discussions of Health Plan Working Groups. They will continue to campaign for a specific Rare Disorders Health Strategy to address inequities, improve health outcomes and to align with international best practice.

Please support Rare Disorders NZ and their collective of rare disorder groups, like ourselves, on **Rare Disease Day, Monday February 28th**. The focus this year is 'GLOBAL HEALTH EQUITY' which provides an ideal opportunity to ask that the Pae Ora (Health Futures) Bill recognises our significant, yet marginalised and vulnerable population group. Rare Disease Day is a day for raising awareness of rare diseases globally and to advocate for recognition and improved access to treatment and care.

What can you do?

- On Rare Disease Day, the PWSA will be sharing a news post and a video featuring one of our members. Please look out for these and share across your social media networks.
- On Rare Disease Day, we will also be sharing the White Paper to be launched by RDNZ, presenting the results of the 'Voice of Rare Disorders survey 2021' (thank you to everyone who took part in this). Please share this fresh evidence for why health inequities for the rare disorder community must be addressed.
- Please share our other videos, images and posts on [social media](#) leading up until Rare Disease Day.
- Check out the [campaign resources](#) on RDNZ's website - tag and post away! #FairforRareNZ #RareDiseaseDay2022

Clinical Trial Opportunity: Tesomet for hyperphagia & weight loss

We are pleased to announce that one of the trial sites for the international phase 2b trial of Tesomet will be in New Zealand. Recruitment has not yet begun in New Zealand due to ethics approval still being processed, but we will forward details once recruitment starts. The phase 2b study aims to recruit 120 participants, aged 13-65 years (initially 18yrs+), who will randomly be given one of 3 different doses or placebo for the first 16 weeks. This initial period will be followed by a 36-week open-label extension where all participants will be treated with Tesomet at the highest tolerated dose as determined in the initial 16 weeks. Inclusion is BMI dependent - view further [trial details](#) or use this [eligibility checker](#).

Tesomet, being developed by [Saniona](#), is a combination of tesofensine (a triple monoamine reuptake inhibitor) and metoprolol (a beta-1 selective blocker). [Tesofensine](#) blocks the reabsorption of 3 monoamine neurotransmitters: serotonin, noradrenaline and dopamine, increasing the levels of these neurotransmitters in the brain, which in turn reduces food cravings and appetite, and increases metabolic fat burn. Phase 2a Step 1 demonstrated clinically meaningful weight loss (6.76%) and a statistically significant reduction in hyperphagia (43%) in adults with PWS at 0.5mg/day, but it was also discovered that plasma levels in PWS patients were higher compared to levels in non-PWS obese subjects, possibly causing the unwanted side effects observed. Therefore, a lower dose was recommended for adolescent PWS patients. [Phase 2a Step 2](#) tested Tesomet in adolescents at lower dose (0.125mg) and was initially completed in January 2019, but a [press release](#) explained that a 24 week extension study was needed to obtain longer-term treatment data at a slightly higher dose for efficacy (0.25mg). Tesomet appeared to be well tolerated at lower doses.

Listening to Voices of people living with PWS around the World

We are very excited to tell you about a new international study we are taking part in by Kamila Lipiec and Kate Woodcock at the University of Birmingham, UK. This is the first international study of its kind that will be surveying people with PWS in order to capture their voice. The study aims to understand how people with PWS feel they fit into society

and what is important to them. The researchers want to find out how we can support people with PWS so that they can achieve the things that are important to them. The study also aims to look at international differences and find out how we can best support people with PWS in different countries.

Many countries are taking part, including: Australia, Italy, France, Spain, Ireland, UK, Malaysia, Canada and USA. We hope to have strong participation from New Zealand as the results will provide us with greater insight, will be of comparative interest, and they will help to inform how we all support people with PWS moving forward.

We are inviting the participation of individuals with PWS aged 16 years or older. The survey is completed online, with 'easy read' support. It asks for short written answers and should take no more than about 45 minutes to complete. People with PWS can ask for support from a caregiver to write down their answers if needed, but the answer has to come from the person living with PWS. Please [contact us](#) if you would like to participate.

A Tribute to Lorna Hayes

It is with sadness we inform you that one of our members, [Lorna](#), passed away peacefully on 9th February 2022, in her 50th year.

Lorna was one of the early members of PWSA(NZ). She lived in Greytown, Christchurch and back in Masterton. Lorna was a special person to many. Lorna and her parents attended some of the first camps and she was always keen to see everyone again. Lorna taught many of us a lot about what it was like to have PWS and we remember her and her family warmly.



Lorna's funeral took place on February 12th, which Cindy tells us was "lovely, funny and very pink." The challenges Lorna faced and met, as a result of PWS, were mentioned. Cindy said it was nice to hear how much the camps meant to Lorna and the whole family.



International PWS Conference

If you're planning some international travel with our border reopening soon, you might want to consider Ireland in your travel plans!

Registration for the 11th International PWS Conference is open now with Early bird registration closing on April 7th.

Visit the [IPWSO conference webpage](#) for further details and registration.

WHEN: 6th – 10th July, 2022

WHERE: University of Limerick

Vacancy: Treasurer

We have a volunteer vacancy on our Board for a Treasurer. If you, or someone you know, would be interested in this role, please get in touch with Charlotte Roos: ceo@pws.org.nz

New Zoom Chat Time (Tweens and Teens)

Soon we will be sending a quick survey to families of this age group to find the most suitable time for all. The Zoom Chat will still be held on the 2nd weekend of the month.

My Workbridge - New Website for Jobseekers

Workbridge has launched an initiative to help disabled Kiwis looking for work - a website called My Workbridge. My Workbridge advertises jobs with supportive employers, provides tools that help with producing a CV, helps users prepare for interviews, and provides information about accessibility. [Read more about it here >](#) Click here for [My Workbridge >](#)

Dates for your Diary

Virtual Social Evening for Parents of 6 - 12 Years - Sun 27th Feb, 7.30pm

Zoom Chat for Adults with PWS - Saturday 5th March, 4pm

Zoom Chat for Tweens and Teens - Saturday 12th or Sunday 13th March, TBC

Virtual Social Evening for Parents of 0 - 5 Years - Sun 27th March, 7.30pm

Transition Expo 2022, Auckland - Wednesday 7th September 2022

PWSA(NZ) Young Families Weekend - Sat 17th - Sun 18th Sept 2022, Wellington

PWSA(NZ) Family Camp - 10th-12th March 2023

Notices / Events

Online Sibshops

Feb 26th, 27th, March 5th, 6th, 19th, 20th

Parent to Parent are now running SibShops online. They are a fantastic connect and support opportunity for children 8-18yrs who have a brother or sister with a disability.

Each sibshop is 2 sessions and you can choose from:

Sat 26 Feb & Sun 27 Feb, 2pm-4:30pm

Sat 5 Mar & Sun 6 Mar, 10am-12:30pm

Sat 5 Mar & Sun 6 Mar, 2pm-4:30pm

Sat 19 Mar & Sun 20 Mar, 10am-12:30pm

Click here for [further information](#) and for the [registration form](#).

Education - Disability and Your Child

March 7th, 14th

by Parent to Parent, funded by Care Matters

Informative and free workshops will lead you through the IEP process, how to have productive IEP meetings, how to foster inclusion in the classroom, and the types of funding available to you.

7 March: 10.30am - Zoom

14 March: 10.30am - Zoom or at 2-12 Commerce Street, Kaitiaia

REGISTER HERE: www.parenttoparentnz.formstack.com/forms/workshop_registration

More info here: www.parent2parent.org.nz/calendar

Annual Transition Expo 2022

2nd PPT date: Weds Sept 7th, 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.