



February 2023 Newsletter

Our thoughts have been with all those recently impacted by floods, the devastation of Cyclone Gabrielle and the ongoing rebuild in these areas. We send aroha to all who may be struggling with the after-effects of these events and encourage you to reach out for support if needed. The following resources may be helpful:

- [Civil Defence Payments](#) available in some areas: call 0800 400 100
- [Community Support Package](#) includes dedicated funding to support disabled people and/or their households, plus funding for community groups, organisations and service providers affected by the North Island floods and Cyclone Gabrielle.
- Disability Helpline: 0800 111 213 or text 8988 (help with general health concerns, if a support worker is unavailable, connecting you with information & support.)
- [Whaikaha - Ministry of Disabled People](#): email contact@whaikaha.govt.nz, phone 0800 566 601 or text 4206
- For health advice: call Healthline 0800 611 116
- Wellbeing & mental health support: [YouthLine](#) 0800 376 633 | text 234, [Depression Helpline](#) 0800 111 757 | text 4202, [The Lowdown](#) text 5626, [1737](#) Need to Talk?
- Power needed for medical equipment or medicine? Contact your power company to let them know and your local civil defence centre for support. If urgent, call 111.
- For welfare assistance: call new MSD helpline 0800 400 100
- [People First easy read information](#) about Cyclone Gabrielle

To all experiencing challenges in the aftermath of these events, kia kaha - especially with the potential for more heavy rain to be heading our way.

National PWSA Camp, March 10th-12th 2023

Following recent extreme weather events, we hope our upcoming camp provides something to look forward to, a welcome change. Our programme is now finalised (click here to [view pdf](#)) and further information regarding groups, packing and accommodation will be sent out soon. Camp numbers are now slightly reduced compared to the high numbers initially registered, so we can accommodate any [last minute registrations](#), but they would need to be confirmed this week. We really do hope that families joining us from Hawkes Bay and Tairāwhiti Gisborne are still able to travel to camp.

Rare Disease Day - Tuesday February 28th


Rare Disorders Month - March 2023

International Rare Disease Day is just one week away! This also marks the beginning of Aotearoa's first ever [Rare Disorders awareness month](#) during March. As part of the RDNZ collective, we are keen to support this initiative and help raise awareness of the challenges faced by those living with rare disorders, and to maintain pressure on our government (especially in an election year) to bring about changes promised.

RDNZ will be marking Rare Disease Day by launching a new parent and caregiver guide, *Raising a child with a rare disorder: A guide for parents and caregivers living in Aotearoa New Zealand*. The launch will take place at Government House, hosted by Her Excellency, The Rt Hon Dame Cindy Kiro. PWSA members will be in attendance, and we look forward to celebrating this occasion with others from the rare disorder community. The guide will be available to download for free from RDNZ's website following the launch.

[#GlowUpShowUp](#) to put a spotlight on issues important to the rare disorder community:

- Order temporary, free tattoos and share an image of them being worn with the hashtag [#GlowUpShowUp](#). Email: RDNZadmin@raredisorders.org.nz
- Rally your friends, school, workplace or community to organise an event, e.g. a colour run, glow up dress up day, a paint and sip event, neon disco, morning tea, fun run or walk. Visit RDNZ's [Get Involved](#) page where you will find helpful packs for different groups.
- Support one of RDNZ's events - buy tickets for [Paintvine](#), or try unique beers at the [Rare Beer Challenge 2023](#).
- Share what you are doing to [#GlowUpShowUp](#) via social media, and share social tiles and captions to help [raise awareness](#).



**GLOW UP
— AND —
SHOW UP
FOR RARE DISORDERS**

- Feb 28th - International RARE DISEASE DAY - Launch of new parent and caregiver guide at Government House, Wellington
- March 2023 - New Zealand RARE DISORDERS MONTH
- March 2nd - PAINT VINE, Harbourside Function Venue, Wellington
Tickets: events.humanitix.com/rare-disorders-nz-paintvine
- March 10th - RARE BEER CHALLENGE 2023 @ Fortune Favours, Wellington, and 16Tun, Auckland, from 5pm

GLOW UP AND SHOW UP FOR RARE DISORDERS MONTH!
GET INVOLVED - ORGANISE AN EVENT AT YOUR SCHOOL, COMMUNITY GROUP, WORKPLACE.

VISIT [RARE DISORDERS NZ](#) FOR IDEAS, GUIDES & RESOURCES.

[#GlowUpShowUp](#) [#DoRightByRare](#) [#RareDisordersMonth](#)

Review of Adult Decision Making Law

Decision-making may be affected due to a learning disability, mental illness, or for other reasons. We'd like to remind you that Te Aka Matua o te Ture | the New Zealand Law Commission are reviewing how the law should respond when capacity for decision-making is affected and seek your experiences and views on how the law could be improved.

Some of the things they are asking about are:

- supported decision-making
- advance directives
- enduring powers of attorney
- welfare guardians
- safeguards and accountability mechanisms

Watch this short [introductory video about the review](#). To learn more, to view the Issues Paper in many accessible formats, or to share your insights / have your say, please visit www.huarahi-whakatau.lawcom.govt.nz (capacity.lawcom.govt.nz)

Submissions can be made via online survey or alternative options **by 5pm MARCH 3RD**.

As any changes to current decision making law have the potential to affect some of our members, the PWSA feels that we could enter a submission on behalf of our association. If you would like to contribute to a representative submission, just [send us a quick message](#) summarising your concerns, views or experiences (**by Thurs 2nd March**).

IPWSO's Mental Health ECHO series

IPWSO are launching a new, [Mental Health ECHO®](#) - a series of presentations and discussions about mental health issues in PWS. Please [share this](#) with any professionals that you are working with.

Starts Tues 28 March, 4pm GMT (4am Weds NZT).



MENTAL HEALTH ECHO®

We are building a community of healthcare professionals and caregivers supporting wellbeing and mental health for people with Prader-Willi syndrome.



Whilst aimed primarily at mental health professionals and professional caregivers who support the wellbeing and mental health of people living with PWS in their work, allied health professionals and parents in supportive roles with their national PWS association are also welcome.

Sessions will include both short and focused presentations by experts on PWS, as well as the discussion of anonymised cases and relevant challenges presented by participants.

Melbourne based, Neuren Pharmaceuticals, announce approval for phase 2 trial of NNZ-2591

The US Food and Drug Administration (FDA) approved Neuren's Investigational New Drug application for NNZ-2591 in PWS, enabling them to proceed with a Phase 2 trial in children. Neuren is developing NNZ-2591 for 4 neurological disorders: Angelman, Phelan McDermid, Pitt Hopkins and Prader-Willi syndromes. Neuren previously reported positive results in the Magel2-null mouse model of PWS, in which treatment with NNZ-2591 for 6 weeks normalised fat mass, insulin levels, IGF-1 levels and all behavioural deficits.

NNZ-2591 is an improved synthetic analogue of cyclic glycine proline (cGP), a peptide which occurs naturally in the brain and is related to IGF-1, an essential growth factor critical for biological balance. During development, the brain and cells that comprise IGF-1 change rapidly in complex ways. IGF-1 and its metabolism play a significant role in regulating these changes. In the mature brain, it plays an important role in responding to disease, stress and injury.

The aim of treatment is to restore the natural balance of brain function by:

- reducing inflammation
- restoring the normal functioning of microglia (immune cells acting as 'gardeners of the brain')
- improving the dendritic structure of synapses (for neuronal communication)
- normalising the levels of IGF-1 in the brain

Find out more from Neuren [here >](#)



New Resources Alert

PWSAUK have produced a new series of short, [educational animations](#) to help explain to people living with PWS about the changes they will experience as they grow up, both physically and emotionally. They cover topics such as puberty, relationships, and advice on interacting with others, both in person and online.

Links to these animations, alongside other resources, can also be found on the [Sexual Development page](#) of our website.

Board Member Vacancy

We are always keen to hear from members who have an interest in becoming more involved in the governance of our organisation. If becoming a Board Member is something you might be considering, please get in touch with our CEO, Charlotte Roos, to ask any questions and discuss further: ceo@pws.org.nz.

Notices / Events

You will notice below that there are no ZOOM CHAT dates advertised for 2023. We are going to be taking a break from hosting these monthly social events and are planning to run more 'one-off' online events for our teen and adult members living with PWS. Each meeting would have its own programme or theme and it will be well advertised beforehand. We would like to discuss ideas for the format of these meetings with those attending the [Adults Living with PWS Leadership](#) meeting at our 2023 camp. If you are not attending camp, but would like to contribute, please click here to [send us ideas](#).

Our virtual social evenings for parents are also paused for now as we review these and make changes in time. We are hoping to host meetings that are more discussion topic based, but we will still have some meetings specific to child age.

Dates for your Diary

International Rare Disease Day - Tues 28th February

Rare Disorders Awareness Month - March 2023

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

IHC Self Advocacy Forums

For individuals living with PWS: Do you want to learn about self-advocacy, make new friends and learn new skills? Would you like to boost your confidence to become more involved with PWSA's Adults Living with PWS (ALPWS) Leadership?

Sign up for these free forums in the following cities:

Weds 1 March - Wellington - 10am to 4pm

Tues 21 March - Christchurch - 10am to 4pm

Weds 29 March - Auckland - 10am to 4pm

Click here for [more information >](#)

To register, please email: ihc.events@ihc.org.nz

Census Day - Tuesday 7th March 2023

The census takes place every five years to better understand how and where people are living. Everyone in Aotearoa New Zealand will be asked questions about themselves. Taking part will ensure you are represented in health care, education and transportation decisions.

The [2023 Census](#) contains a new question on disability and will ask people whether a disability, long-term condition, or mental health condition limits their ability to carry out activities of daily living.

Support is available to complete the census. Instructions and information are also available in different formats, including [Easy Read](#). You can choose to do the census online or on paper forms (these can be ordered for free).

Click here for [census support >](#)

Many regional events and workshops are now being presented online. 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.