

September 2022 Newsletter



Young Families Weekend

Following Covid-19 postponements, we were finally able to hold our Young Families Weekend in Wellington earlier this month. It was lovely to be able to connect in person once again. A brief [feedback survey](#) has been sent to those who were invited or attended. This is really useful for planning future events and to include in future funding requests. If you haven't sent feedback already, please consider doing so - all feedback is welcome and can be submitted anonymously. Click here to [read more about the weekend >](#)

PWSA Events Coming Up...

Whānau Camp

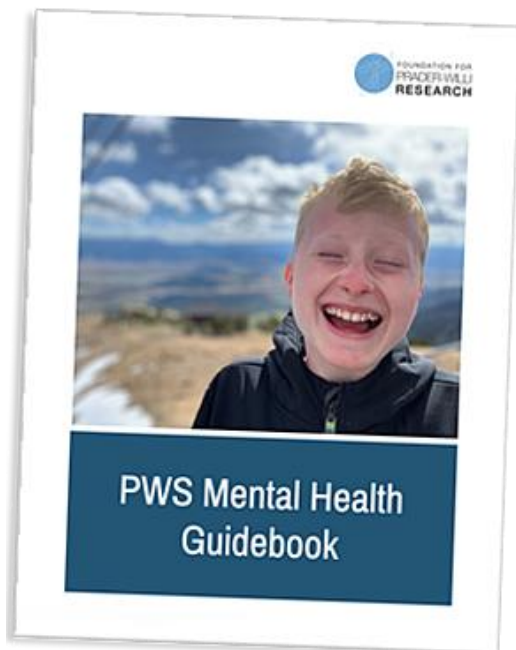
Now that our in-person events are up and running again, we would like to remind you about our [Family Camp at Taupo in March 2023](#). When the camp was postponed, all registrations and payments were rolled over. Soon, we will be sending an email to all those who previously registered in order to check that their registration details are still correct and to confirm any payments we have received. If you have not registered and would like

to do so, this can be done using our [online registration form](#), until all spaces are filled. A reminder that our camp is for people living with PWS of all ages to attend with their family or a support worker. Please note that due to the large numbers attending our camps and the short time available to fit everything in, the instructor led activities are only for those living with PWS and child siblings. A bit nearer the time, we will also be looking for some kind volunteers to help with running some of the activities.

Regional Events

As the end of the year approaches, we are keen to facilitate some regional gatherings. Ideally these would be held in October / November before everyone gets too busy with end of year events. If you are interested in being a point of contact for a get-together in your area, please [contact us](#) - we can help with the sharing of information, managing RSVPs and provide some funding. All you need to do is suggest a venue, suitable date and be a point of contact on the day! Suggestions might be a day out at a wildlife centre, a picnic or BBQ in the park, meeting at a local kindy or community hall, or an activity such as ten-pin bowling. We are particularly keen to hear from members keen to help coordinate an event in the Auckland area. Details of a regional event near you coming soon...

Mental Health Awareness Week



For Mental Health Awareness Week, we are sharing some useful resources:

PWS Mental Health Guidebook

In-depth resource by Lauren Schwartz Roth based on interviews with family members of individuals living with PWS, as well as experts in mental health. To download, scroll down the FPWR web page to insert your email.

IPWSO Mental Health web page by Tony Holland, Emeritus Professor of Psychiatry at Cambridge University and President of IPWSO.

The Mental Health of People with PWS with Specific Focus on Mood Disorders and Psychotic Illness

Fact sheet containing the info on above web page by Tony Holland.

Mental Health and Behaviour Changes: when should parents seek help? by Drs Jan Forster and Linda Gourash (Pittsburgh Partnership) and Kathy Clark (PWSA USA).

PWSA(NZ) Mental Health web page - Overview of psychiatric disorders in PWS, tips, recognising signs and getting help, plus links to many further resources.

[Serious Mental Health Problems in PWS, by FPWR](#) - Identifying changes in mental health, getting help and beginning treatment, plus special considerations for PWS.

[IHC Library free loan resources](#) - books for children and adults

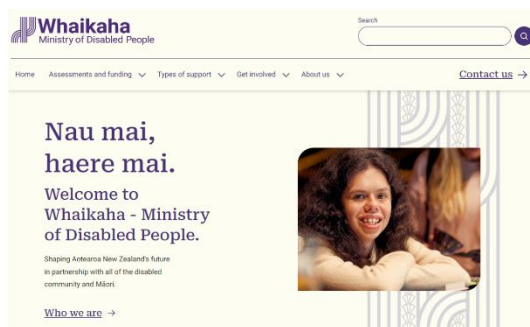
Updated Medical Resource

IPWSO have revised their one-page resource for doctors, 'Important medical facts about PWS'. It contains information about 12 key issues and is available on IPWSO's website and from our [resources page](#) >



Carer Support and IF - Ongoing Flexibility

Whaikaha, Ministry of Disabled People, have announced that the increased flexibility for IF and carer support, initiated in response to the outbreak of Covid-19, will continue until February 28th 2023. This temporary exemption allows the employing of family, whānau and āiga who live in the same household and allows you to purchase items that would provide you with a break.



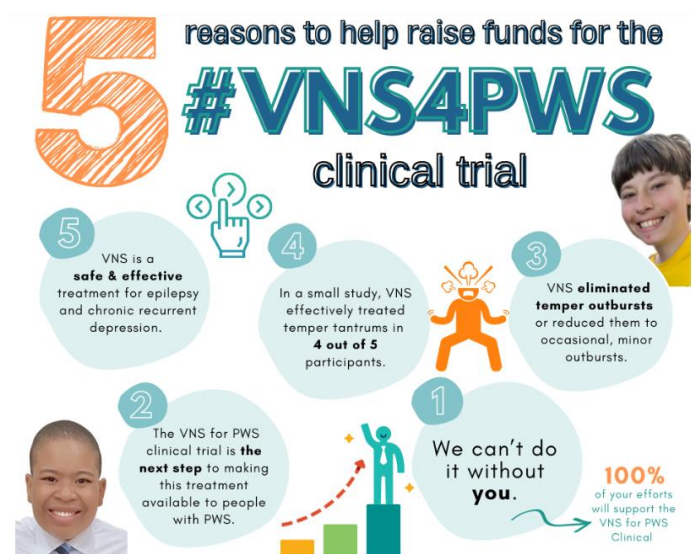
Whaikaha Website

Have you checked out the website for the new Ministry of Disabled People yet? You will find lots of useful information such as: details for your local NASC (Needs Assessment Service), support and respite options for carers, and how to have your say. Click here to [visit Whaikaha](#) >

Vagus Nerve Stimulation for Behaviour in PWS

You may be aware of a focused [campaign](#) by the Foundation for Prader-Willi Research (#VNS4PWS) to [raise funds](#) toward a multi-centre, large-scale and costly trial of VNS in the USA, but it is hoped that this use of funds could be the most impactful to date.

So, what is vagus nerve stimulation?



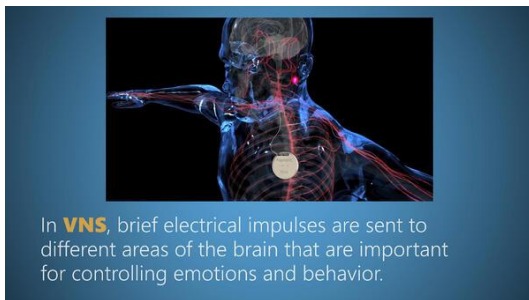
5 reasons to help raise funds for the #VNS4PWS clinical trial

- 1** We can't do it without you.
- 2** The VNS for PWS clinical trial is the next step to making this treatment available to people with PWS.
- 3** VNS eliminated temper outbursts or reduced them to occasional, minor outbursts.
- 4** In a small study, VNS effectively treated temper tantrums in 4 out of 5 participants.
- 5** VNS is a safe & effective treatment for epilepsy and chronic recurrent depression.

100% of your efforts will support the VNS for PWS Clinical

VNS alters the activity of nerves to stimulate brain areas which are involved in controlling emotions and behaviour. It previously involved surgically implanting a device that sends regular short electrical pulses through the vagus nerve in the neck, but transcutaneous vagus nerve stimulation (t-VNS) can now be used, which is where an external device is worn in the left ear and an electrode stimulates the auricular branch of the vagus nerve.

In 2015, a [preliminary study](#) conducted at the University of Cambridge reported that 2 out of the 3 participants and their carers observed consistent, beneficial effects on maladaptive behaviour, temperament and social functioning. A larger follow-up [proof of concept study](#) which used external (rather than surgically implanted) vagus nerve stimulators was initiated with [findings published in 2019](#) revealing, "4 of the 5 participants who completed the study exhibited a statistically significant reduction in number and severity of temper outbursts after approximately nine months of daily four-hour t-VNS." Treatment was found to be safe and effective. Success has been associated with increased activation of neurotransmitter systems and in particular, increased brain levels of gamma-aminobutyric acid (GABA), a neurotransmitter which is known to be [reduced in some people with PWS](#).



You can watch the [VNS for PWS webinar](#) to find out more about this promising potential treatment.

You may also want to share this brief [VNS for PWS 2022 fundraising video](#).

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

Dates for your Diary

Zoom Chat for Adults with PWS - Saturday 1st Oct, 4pm CANCELLED

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

Zoom Chat for Tweens and Teens - Saturday 8th Oct, 4pm

Virtual Social Evening for Parents of Teens/Adults - Sun 30th October, 7.30pm

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

Virtual Social Evening for Parents of 0 - 5 Years - Sun 11th December, 7.30pm

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

Planning for Adulthood

Mon 17th Oct 6.30-9.30pm ZOOM, Mon 21st November 11.30-2.30pm ZOOM

Hosted by Disability Connect, a presentation by Nan Jensen (Barrister and Solicitor) from Quinlaw. This seminar covers the legal framework around disability and disability rights.

Click here for [more information and to book \(RSVP essential\)>](#)

Education Legal Issues

Weds 19th Oct 12.00-2.15pm ZOOM

Hosted by Disability Connect, a presentation by Nan Jensen (Barrister and Solicitor) from Quinlaw. This seminar covers school rules and discipline, what is legal, reasonable and what can be expected.

Click here for [more information and to book \(RSVP essential\)>](#)

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.