PWS PRADER-WILLI SYNDROME
ASSOCIATION NEW ZEALAND
ADVOCACY · EDUCATION · SUPPORT

APRIL 2026 NEWSLETTER

PWSA Update

This is our first newsletter for 2026, and we have lots to share! It has been a busy start to the year, with reregistration as an incorporated society, submission of a response to the Draft Carers Strategy Action Plan, delivery of five provider training workshops across Aotearoa New Zealand, and early progress on a campaign to extend PWS-specific residential support options. I also met with the Health Quality and Safety Commission to outline the health concerns of our PWS community - thank you to everyone who provided examples that I was able to collate into clear, common themes.

In January, we held our first regional event of the year, with families meeting at Zone Bowling Garden City in Christchurch. This get-together was originally intended to be a picnic in the park, but when the weather didn’t play along, we moved to plan B. Cindy and Mike kindly hosted this event, which was attended by 11 people living with PWS, along with their families or support persons.

Click here to view photos>

We would love to support more Regional Hub get-togethers. If you would like to organise an event, please let us know so we can help with advertising and funding. If you haven't joined a Regional Hub yet, you can sign up here>

Unfortunately, we have had to postpone the Young Families Weekend, initially planned for May for families with children aged 10 and under. We now plan to hold this event in spring and will be in touch with families soon about this. However, we are pleased to share that our next family support camp is confirmed and will take place at Carey Park in Auckland on the weekend of March 12th-14th March 2027 - SAVE THE DATE!

Our RURU Leadership Group held their first meeting of the year in March, where they learned about peer support. The group were keen to offer peer support to others living with PWS, particularly younger individuals, and wanted to think more about how this could work. If you have any ideas about this, please get in touch. The RURU Group also selected their representatives for 2026 - Owen and Richard F. They would love to see more adults living with PWS at the next meeting on June 15th. The group now has its own newsletter - if you are an adult living with PWS and have not received a copy, please forward an email address to receive future editions.

On a personal note, I would like to ask families to please sign and share my parliamentary petition calling for compulsory training for staff supporting individuals with specific health needs.

Disorder-specific training for disability support staff is vital, but there has been a lack of clear expectations and oversight regarding training requirements.

Sign the Parliamentary Petition

Call for a mandatory requirement that disability support service organisations provide disorder-specific training for staff prior to working with individuals living with a health disorder or condition.

https://bit.ly/45cFeVo

I continue to fight for justice for Jacob and for the case to be heard in court. You may have seen media coverage in January when the HDC's report was released.

I appreciate that it can be upsetting for families to hear how things can go so badly wrong, but please know that these circumstances are not characteristic of residential services or the transition process that would normally be followed. What happened to Jacob involved an extreme level of negligence, including multiple serious failures and an inappropriate placement decision that our family was not given opportunity to be involved in.

I want to reassure families that this is not typical of care usually provided to individuals living with PWS in residential services, many of which regularly engage in PWS training.

Ngā mihi, Jo Davies, CEO

In Memorium

It is with great sadness that we share the news that Rachel Kenny passed away in March at the age of 52 years. Rachel lived most of her life in Palmerston North and was a very active member of the People First organisation. She was also on an advisory committee in the establishment of Enabling Good Lives. She was a very strong advocate for others, with a great personality and sense of humour.
Rachel and her family were one of the five families who first met and helped form our Association in the 1980s.

We also share the sad news that Jackie Collins passed away in March, aged 54. Jackie was a resident at Brackenridge in Christchurch from its opening in 1999 and had lived at the Templeton Centre prior to this. This photograph of Jackie was taken at the PWSA Christchurch family's get-together earlier this year, which Jackie enjoyed attending.

We extend our condolences to the families of Rachel and Jackie, and the staff who supported them.

Experiences of whānau Māori and PWS

Aaron Hāpuku at the University of Canterbury is still keen to hear from whānau Māori who may be interested in participating in research investigating the experiences of whānau Māori and Prader-Willi syndrome.

If you are interested or have questions, please make contact with Aaron: aaron.hapuku@canterbury.ac.nz

Koha will be offered to participant whānau for sharing their time, kōrero and pūrākau (stories, narratives). Data for this project will be collected through wānanga (whānau interviews), interviews and PhotoVoice (photographs/artwork).

Participant whānau needed for research investigating the experiences of whānau Māori and Prader Willi Syndrome.

This research study is being conducted as part of the requirements for the Doctor of Health Sciences (DHSc) degree through the University of Canterbury Faculty of Health | Te Kaupeka Oranga

Whānau with a Prader Willi Syndrome whānau member residing in Aotearoa, New Zealand are encouraged to make contact

Koha will be offered to participant whānau for sharing their time, kōrero and pūrākau (stories, narratives) on the experiences of whānau Māori who live with Prader Willi Syndrome.

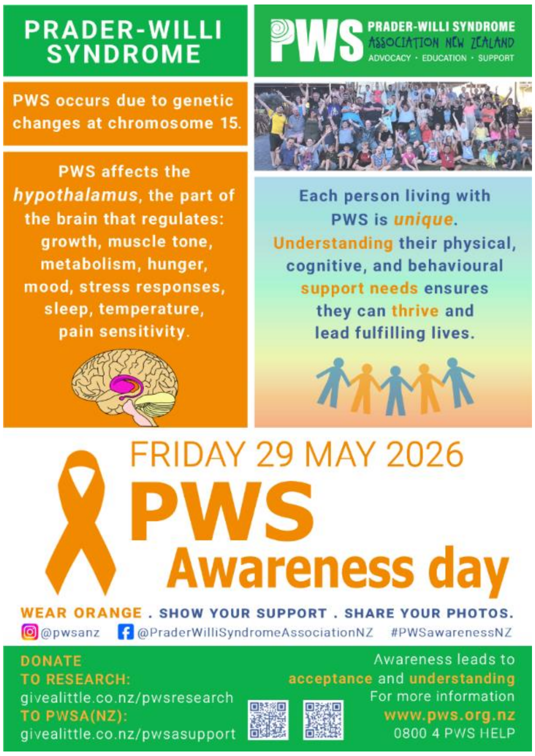
Data for this project will be collected through wānanga (whānau interviews), interviews and PhotoVoice (photographs/artwork).

This study has been reviewed and approved by the University of Canterbury Human Research Ethics committee and has undergone UC Māori ethics consultation

If your whānau, or someone you know might be interested, please contact: Aaron Hāpuku
aaron.hapuku@canterbury.ac.nz
https://profiles.canterbury.ac.nz/Aaron-Hapuku

UC
UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Get ready for PWS Awareness Month this May!



PRADER-WILLI SYNDROME

PWS PRADER-WILLI SYNDROME ASSOCIATION NEW ZEALAND
ADVOCACY · EDUCATION · SUPPORT

PWS occurs due to genetic changes at chromosome 15.

PWS affects the *hypothalamus*, the part of the brain that regulates: growth, muscle tone, metabolism, hunger, mood, stress responses, sleep, temperature, pain sensitivity.

Each person living with PWS is *unique*. Understanding their physical, cognitive, and behavioural support needs ensures they can thrive and lead fulfilling lives.

FRIDAY 29 MAY 2026
PWS
Awareness day

WEAR ORANGE . SHOW YOUR SUPPORT . SHARE YOUR PHOTOS.
@pwsanz @PraderWilliSyndromeAssociationNZ #PWSawarenessNZ

DONATE
TO RESEARCH:
givealittle.co.nz/pwsresearch
TO PWSA(NZ):
givealittle.co.nz/pwsasupport

Awareness leads to acceptance and understanding
For more information
www.pws.org.nz
0800 4 PWS HELP

As per usual, we have posters, ribbons and wristbands available to help you run an awareness event. These are only available to be ordered during the next week, but posters can be downloaded at any time. LAST POSTING DAY for ribbons, wristbands and posters is MONDAY 4TH MAY. Orders need to be received by **FRIDAY 1ST MAY**.

This year, we also have new T-shirt designs coming soon on digitees, and there will also be awareness necklaces available to order - details to follow.

PWS Awareness Month is also a fantastic opportunity for fundraising and making use of our Givealittle platforms.

Order Resources Here

Pharmac News and Consultation on NPPA

We were pleased to hear Pharmac's decision not to proceed with the proposed changes to how it manages the Options for Investment list. PWSA submitted a response to this proposal last year, which would have meant some of the lowest-ranked medicines on the OFI list being declined. Growth hormone for adults living with PWS is currently on the OFI list awaiting funding, but its priority ranking is unknown as Pharmac do not disclose this information.

Pharmac is currently reviewing its Exceptional Circumstances Framework, which includes the NPPA policy (Named Patient Pharmaceutical Assessment). We understand that some individuals living with PWS may have medications funded through an NPPA, but Pharmac is assuring patients that an existing named patient approval will remain in place, regardless of the outcome of their review.

The review of the Exceptional Circumstances Framework is intended to improve equitable outcomes in Pharmac's decision-making processes, one of the directives of the 2022 Pharmac Review. The review aims to strengthen the Framework and NPPA policy, which will include improving how rare disorders are considered and addressed within the Framework. Some of the current issues include lack of information and clarity about when an application can be made and the process involved.

PWSA is considering submitting feedback to this review and would like to hear about any experiences with NPPA applications. Please forward any experiences or views about Framework fitness for purpose. These can be sent to: jo.davies@pws.org.nz

You can also submit your own feedback, and we particularly urge you to do so if you have experience of an NPPA application being declined. Pharmac are providing several ways to engage with this consultation, including via online form>

Consultation closes 7 June 2026.

NPPA experiences to PWSA >

Mental Health and Wellbeing Consultation

The Ministry of Health is currently seeking feedback on the draft Mental Health and Wellbeing Strategy 2026 - 2036 and we strongly recommend taking a moment to complete an online survey. The Strategy will guide how the health system improves mental health and wellbeing over the next 10 years, including a three-year implementation plan.

Inadequacies in mental health support for patients living with PWS is a subject we frequently hear about. Some of the issues affecting people living with PWS:

- difficulties in accessing mental health services
- mental health issues being 'brushed off' as part of the syndrome
- being discharged from mental health services when oversight is still required
- lack of psychiatric expertise in PWS
- need for a more holistic and collaborative approach to patient wellbeing
- unavailability of medications (guanfacine)

We would very much like to see professional development opportunities for psychiatrists to learn about PWS and to see links formed with Centres of Expertise.

Ideally, patients would also have opportunity to see a mental health specialist whilst attending a multidisciplinary PWS clinic appointment, proactively focusing on early intervention to avoid the 'ambulance at the bottom of the cliff'.

Consultation closes at 5pm on 18 May 2026.

Complete a Survey

PWS Conference - Brisbane

Prader-Willi Research Foundation Australia is hosting a 3-day PWS Conference featuring plenary speakers, Professor Jennifer Miller and Associate-Professor Laura de Graaff.

Jennifer Miller is a paediatric endocrinologist and researcher who has worked with individuals living with PWS for more than 20 years and investigated emerging therapies, nutrition for PWS, and treatments for hyperphagia.

Laura de Graaff is a genetic and developmental endocrinologist who co-founded and leads the adult department of the Dutch Centre of Reference for Prader-Willi syndrome, where her multidisciplinary team has supported more than 210 adults living with PWS. She is a leading international voice in the care of adults with Prader-Willi syndrome.

Visit the conference website to view the conference programme and registration details.

IPWSO Professional Caregivers' Forum Meeting

The last forum meeting was on '**Ageing in PWS**' and took place in January at a rather unsociable hour for our part of the world, but you can visit the Forum Newsletters page to view presentations, summary notes and newsletters.

We encourage residential service providers and support staff to join the next Forum meeting:

Topic: **Nutrition, Structure, and Safety in PWS Residential Care Settings**.

Date: **Friday 22nd May**
Time: **7am NZST**

To receive the link for this meeting, you need to join the Caregivers' Forum.

Anyone working in a paid role supporting individuals living with PWS is welcome to join the forum, supported by the Professional Providers and Caregivers Board (PPCB) of IPWSO, an advisory board dedicated to sharing best practice, information, knowledge and techniques.

Join the Forum

New Resource Alerts

Like many others with PWS, I like routines

Support Me to Be Independent

I want to do things for myself, even if I need some help.

I like to feel proud of myself.

What helps me:

- Give me safe jobs to do, like cleaning or gardening
- Give me choices I can understand, such as 'Do you want to go to the gym or swimming?' You might need to explain them more than once
- Celebrate when I learn something new

See Me, Not Just Prader-Willi Syndrome

An everyday guide for people supporting individuals with PWS.

Written by people with PWS.

Every person deserves to be treated with kindness and understanding.

See Me, Not Just Prader-Willi Syndrome

This booklet is a guide for people supporting individuals with PWS which was co-created with adults living with PWS through the UK's Owl Focus Group.

It is designed for people living with PWS to personalise and share with their carers or support providers to help them better understand their individual needs.

Click here to view and download>

New Resource Spotlight

Respiratory (Breathing) Concerns in Prader-Willi Syndrome (PWS)

A Guide for Parents and Caregivers

This document was developed with support from a grant provided by

Respiratory Concerns in PWS

People living with PWS can be more vulnerable to breathing challenges, including during sleep and sickness.

This guide covers common concerns, swallowing risks, how breathing is evaluated, caregiver tips, and even some simple breathing games to help expand the lungs.

Click here to view and download>

Guardianship Policy examples for Medical Centres, Residential Providers

With the right care and support, people with PWS can now live longer and healthier lives. However, in too many cases, a lack of understanding of the syndrome results in warning signs of injury and illness being missed - with devastating consequences. This is one reason why parents sometimes apply to become Welfare Guardians of their adult son or daughter, so that they can inform and advocate as needed, in addition to supporting decision-making.

Unfortunately, even with a Welfare Guardianship order in place, there have been instances where the order has not been observed and parents have not been notified of concerning changes in health or behaviour.

If you have a guardianship court order in place, we recommend asking your medical centre or support provider to view their guardianship policy and check that it stipulates a requirement to notify you of any concerns. If they do not have a guardianship policy, please feel free to share the examples below which they are welcome to adapt.

These policies have been developed in collaboration with one of our parent Members.

Example guardianship policy for medical centres>

Example guardianship policy for residential providers>

PWS Research News

Pause of the HERO trial (ARD-101)

You may have heard the news that Aardvark Therapeutics have announced a voluntary pause of their global phase 3 HERO trial investigating ARD-101 for hyperphagia in PWS. Data from phases 1 and 2 was very promising with no safety concerns reported, but data obtained in a study of healthy volunteers at higher doses than those used in the HERO trial has shown reversible cardiac observations in some patients. As a precautionary measure, the HERO trial has been paused whilst this data is reviewed. Aardvark remain hopeful that the trial can be restarted once safety checks are complete.

Hypogonadism and its Management in Adolescents with PWS

A recently published Australian study aimed to describe the spectrum of pubertal development, and the diagnosis and treatment of hypogonadism in paediatric/adolescent patients with PWS. They found that spontaneous puberty onset occurred in 63% of females and 68% of males with onset at a median age of 10.3 years in females and 12.3 years in males. However, most of the study cohort demonstrated hypogonadism (lack of sex hormones and pubertal arrest) before transitioning to adult care, diagnosed at a median age of 14.1 years in females and 15.3 years in males.

Hypogonadism was found to be predominantly central (pituitary/hypothalamic dysfunction) rather than primary. However, primary (testicular failure) and mixed forms were present in males. It was thought that slower progression of gonadal failure in females with PWS than males may explain reports of pregnancies in females with PWS, while no males with PWS have been recorded to have fathered a child.

Hypogonadism can cause incomplete puberty, infertility, fatigue, loss of muscle mass, and weakened bones (osteoporosis).

This study emphasises the need for ongoing pubertal assessment. Clinicians often wait to start treatment for hypogonadism in PWS until the mid-pubertal age when clinical signs of stalled puberty or biochemical changes can diagnose hypogonadism, but finding the optimal time to start treatment can prove difficult and even those treated with hormone replacements in this study cohort had not reached an advanced clinical pubertal stage by their last paediatric visit. This may suggest clinician reluctance to escalate doses appropriately through adolescence. Read the full paper >

Experiences and Support Needs of Siblings

Researchers in the UK recently reviewed studies examining the experiences of having a sibling diagnosed with Prader-Willi syndrome, including their previous qualitative study. Three themes emerged: psychological impact, influence on family relationships, and the effect of familial characteristics.

Researchers found a notable tendency towards negative psychological experiences, such as stress and burden. Sibling experiences were complex, with concerns about adding to their parents' burden and mixed feelings towards their sibling with Prader-Willi syndrome. Negative impact appeared exacerbated by the intensity of behavioural problems, which also affect sibling relationships. They also noted that practices around food security and mealtimes can potentially result in negative attitudes towards food in the sibling. Generally, siblings viewed the focus on their brother or sister with Prader-Willi syndrome as negatively affecting their family life and compounded their experiences outside the family home, where they felt lonely and misunderstood.

The researchers also noted that positive aspects of the sibling experience had limited coverage in the included studies, but there were examples of joint activity enjoyment, strong sibling bond and affection, particularly if the person with PWS was sufficiently active and younger than the sibling. They concluded that “Findings foreground the need for a family-centered approach in future research and practice..."
Read the full paper>

Effects of Probiotics in PWS

Definitive conclusions cannot be drawn about the effects of probiotics as a treatment in PWS, but this review found some promising effects were observed, particularly in the area of social participation, although overall positive impact appeared relatively modest. It is thought that probiotics may help alleviate some gastrointestinal symptoms, but a lack of data remains. Probiotic supplementation was found to be safe with no significant increase in gastrointestinal adverse events.

Reminder about GLP-1 safety considerations

As mentioned in our last newsletter, GLP-1 agonists are being prescribed more frequently (**Trulicity and Wegovy**) and we want to remind you of the need for caution due to the safety of these medications still being evaluated in PWS. Careful monitoring is required if proceeding with treatment. Case studies have shown these medications can help with weight management, but large-scale trial data is lacking and there are concerns about the potential for gastrointestinal side effects.

GLP-1 agonists slow the rate at which food leaves the stomach which means people feel full for longer, but it needs to be considered that gastric emptying already tends to be slow in PWS and there are well known gastrointestinal risks if someone were to continue overeating with a full stomach.

Assoc Prof Tania Markovic at the University of Sydney is currently investigating Tirzepatide (Mounjaro) for safety in PWS, another GLP-1 agonist, and we look forward to gaining insights from this study, especially as Mounjaro is currently being considered for approval in New Zealand.

Benefit-risk should be assessed on an individual basis. When discussing this with your doctor before starting treatment, we recommend asking them to take a look at the recommendations of a clinical workshop convened by FPWR: the efficacy and safety of GLP-1 agonists in PWS>

Additional Research Participation Opportunities

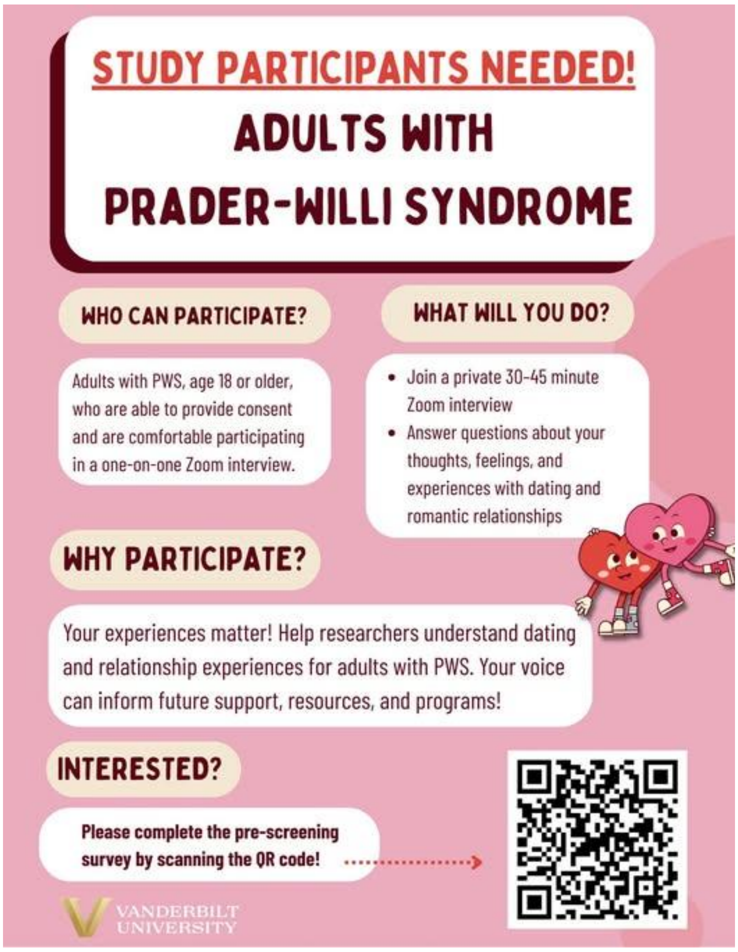
How adults living with PWS understand and experience relationships, specifically romantic relationships.

We have been asked to share these details by Naomi from Dr. Elisabeth Dykens' lab at Vanderbilt University.

Participants do not need to be dating or in a romantic relationship to take part. It is perceptions, experiences, and understanding of relationships in general that the researchers are interested in.

The study involves a brief online screening survey and, if eligible, a virtual interview. See the flyer for details.

Pre-screening survey>



STUDY PARTICIPANTS NEEDED!

ADULTS WITH PRADER-WILLI SYNDROME

WHO CAN PARTICIPATE?

Adults with PWS, age 18 or older, who are able to provide consent and are comfortable participating in a one-on-one Zoom interview.

WHAT WILL YOU DO?

- Join a private 30-45 minute Zoom interview
- Answer questions about your thoughts, feelings, and experiences with dating and romantic relationships

WHY PARTICIPATE?

Your experiences matter! Help researchers understand dating and relationship experiences for adults with PWS. Your voice can inform future support, resources, and programs!

INTERESTED?

Please complete the pre-screening survey by scanning the QR code!

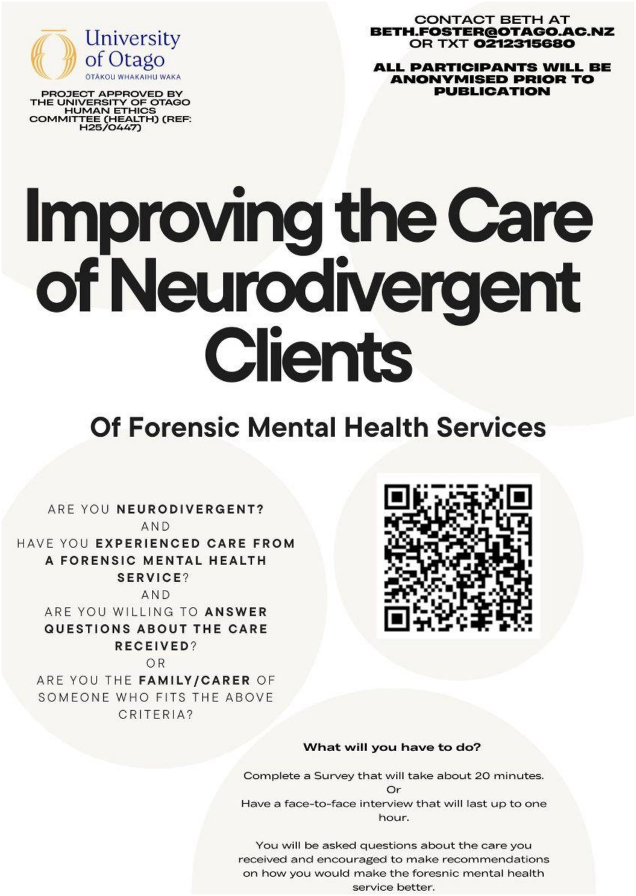
VANDERBILT UNIVERSITY

Care of neurodivergent clients accessing forensic mental health services.

This research may be relevant to some of our members. Beth Foster at the University of Otago wants to hear from people who have a neurodiverse condition and have experienced care from a forensic mental health service. Alternatively, she would like to hear from the family or carers of neurodivergent individuals who meet the criteria above.

Participation involves a 20-30 minute anonymous survey or a face-to-face interview.

Click here to participate>



University of Otago
ŌTĀKOU WHAKAIHU WAKA

PROJECT APPROVED BY
THE UNIVERSITY OF OTAGO
HUMAN ETHICS
COMMITTEE (HEALTH) (REF:
H25/0447)

CONTACT BETH AT
BETH.FOSTER@OTAGO.AC.NZ
OR TXT **0212315680**

ALL PARTICIPANTS WILL BE ANONYMISED PRIOR TO PUBLICATION

Improving the Care of Neurodivergent Clients

Of Forensic Mental Health Services

ARE YOU **NEURODIVERGENT?**
AND
HAVE YOU **EXPERIENCED CARE FROM A FORENSIC MENTAL HEALTH SERVICE**?
AND
ARE YOU WILLING TO **ANSWER QUESTIONS ABOUT THE CARE RECEIVED**?
OR
ARE YOU THE **FAMILY/CARER** OF SOMEONE WHO FITS THE ABOVE CRITERIA?

What will you have to do?

Complete a Survey that will take about 20 minutes.
Or
Have a face-to-face interview that will last up to one hour.

You will be asked questions about the care you received and encouraged to make recommendations on how you would make the foresnic mental health service better.

Response to anaesthesia in PWS.

A small number of cases have been reported to IPSWO which describe mental health decline after surgery. This appears rare and risk factors remain unclear. The aim of this study is to better understand the problem and whether risk factors can be identified to prevent complication. Participation involves caregivers completing a 30-minute survey if eligible.

RESPONSE TO ANAESTHETIC IN PEOPLE WITH PWS STUDY

WHO IS ELIGIBLE:

Carers/ guardians or family members who look after people who have genetically or clinically diagnosed PWS and have the following:

- at least 1 past surgical procedure requiring general anaesthesia since 2015
- were 12-65 years old at time of the anaesthetic

Scan here to access the survey and use the codeKCY7JHAYX

Who is eligible?
Carers / guardians or family members who look after people who have a diagnosis of PWS and have the following:

- at least 1 past surgical procedure requiring general anaesthesia since 2015
- were 12-65 years old at time of the anaesthetic

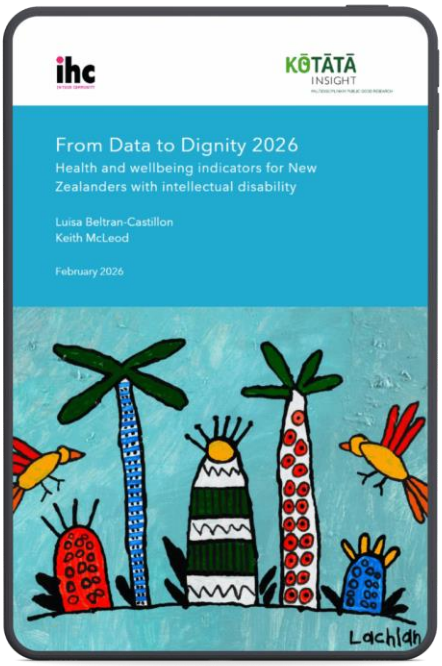
The research team want to hear from those who did not experience mental health problems after surgery as well as those who did. For more information, you can contact watch this video or contact an Asia/ Oceania study representative:
Janet Franklin: Janet.franklin@health.nsw.gov.au, or
Georgina Loughnan: Georgina.loughnan@pws.org.au

To access the survey, scan the QR code or click this link and insert code: KCY7JHAYX

Other News from Aotearoa New Zealand

During March Rare Disorders Month, RDNZ launched their latest White Paper on the impact of living with a rare disorder in New Zealand. The white paper was informed by the 2025 Voice of Rare Disorders survey findings in which the PWS community was well represented.

This event was attended by the Minister of Health, health officials, researchers and clinicians.


ihc

KŌTĀTĀ
INSIGHT

From Data to Dignity 2026
Health and wellbeing indicators for New Zealanders with intellectual disability

Luisa Beltran-Castillon
Keith McLeod

February 2026

Lachlan

Also released in March, IHC launched their latest report on the health and wellbeing of New Zealanders with intellectual disabilities, Data to Dignity 2026. This report builds on the 2023 findings and calls for action to address inequities and reduced health outcomes.

Dates for Your Diary...

Last day to order ribbons and wristbands - Friday 1st May
Last day for Committee nominations for AGM - Friday 1st May
PWSA(NZ) Annual General Meeting - Sunday 10th May @ 4pm
Mental Health Consultation closes - Monday 18th May @ 5pm
IPWSO Caregivers Forum Meeting - Friday 22nd May @ 7am
PWS Awareness Day - Fri 29th May
Pharmac NPPA Consultation closes - Sunday 7th June
Next RURU Group meeting - Monday 15th June @ 6.30pm
PWRFA Conference - Fri 28th - Sun 30th August 2026
Family Support Camp - Fri 12th - Sunday 14th March 2027

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Contact Us:
www.pws.org.nz | enquiries@pws.org.nz | 0800 4 PWS Help