

## JULY 2026 NEWSLETTER

### PWSA News Updates

We held our Annual General Meeting in May and welcomed two new Officers to our Committee, Bjørn Christensen and Sam Quinn.

Bjørn is a service delivery lead with Community Connections for Wellington and Kāpiti services. He is passionate about achieving the best outcomes possible for the people he supports, including looking to innovative ways that other countries are utilising support models.

Sam also has a background in residential service management. She strongly believes in person-centred thinking and considers this fundamental to working effectively with people living with a disability. Sam has committee and governance experience and is looking forward to bringing her skills and experience to PWSA(NZ).

#### New PWSA Chair

The Committee also elected a new Chair at the AGM and we are pleased to announce Sarah Verran as our new Chairperson. We are very excited and grateful for the strategic vision and experience Sarah will bring to the Committee.

Sarah joined our Committee in 2025 after attending a family support camp with her adult daughter, who lives with acquired Prader-Willi syndrome symptoms. Inspired by the strength of the PWS community and the importance of connection and support, Sarah volunteered to become our Chair.

Based in Cambridge, Sarah brings extensive national governance experience across the disability and community health sectors. In her day job, she is the Chief Executive of a national community health organisation, where she is passionate about strengthening services, building partnerships and ensuring people and whānau have access to the support they need.

Sarah's leadership is shaped not only by her professional experience, but also by lived experience. When her daughter sustained a life-changing brain injury as a child, her family's world changed forever. Navigating the health, disability and education systems has given Sarah a deep understanding of the challenges many families face, as well as the importance of compassionate, person-centred support, strong advocacy and collaborative leadership.

Known for her positive outlook and ability to bring people together, Sarah values open communication, strategic thinking and building meaningful relationships. She believes good governance is about listening, creating opportunities and ensuring organisations remain focused on the people they exist to serve.

Sarah feels honoured to support the Prader-Willi Syndrome Association (NZ). She is deeply committed to working alongside the Committee, members, families and the wider community to strengthen awareness, connection and support for everyone affected by Prader-Willi syndrome throughout Aotearoa New Zealand.



## Annual Performance Report

Our Annual Report for 2025 was presented at the AGM. This is available to [read online >](#)

## PWSA(NZ) Advocacy

Since our last newsletter, PWSA(NZ) has lodged 3 public submissions:

- Feedback to the Ministry of Health's consultation on the draft Mental Health and Wellbeing Strategy 2026 – 2036.
- A response to Pharmac's review of its Exceptional Circumstances Framework, which provides pathways for individuals to access funded medicines when their complex needs cannot be met through the pharmaceutical schedule. The ECF includes the Named Patient Pharmaceutical Assessment (NPPA) policy.
- A response to the Social Services and Community Select Committee opposing the Disability Support Services Bill.

These submissions can all be found under 'Advocacy Updates' on our [News page >](#)

We would also like to say well done to Sarah McLarin from Nelson who presented an oral submission on the DSS Bill to the Select Committee, which you can [watch here >](#)

---

## PWS Awareness Month News



A group of kaimahi wearing various items of orange clothing and accessories, posing for a photo in the office. They smile happily.

We would like to thank Shelley Mitchell from Christchurch and Greta Gotlieb from Auckland for their amazing contributions to raising PWS awareness during May.

Shelley made a huge number of orange necklaces which she sold to PWSA members, and through her own awareness and fundraising event. Shelley raised a fantastic total of \$1330 for PWSA(NZ)!

Greta volunteered to design some new Tshirts for us which were sold through our [digitees store](#). These were very popular and look fabulous!

In the image above, you can see Sarah Jeffares wearing one of Greta's new designs during a Go Orange for PWS Day held at Whaikaha. Sarah organised the event in honour of her niece Amy and others living with PWS. Sarah also shared some information about Amy and PWS on Whaikaha's office intranet. Thank you for raising awareness, Sarah.

### Why you'll want to wear orange this Friday

Published 25/05/2026 - 3 min read

Do you enjoy having Programme Lead Sarah Jeffares as a colleague? Well, you have her niece Amy to thank:



Amy and Sarah standing side by side in 2026, both grinning at the camera in matching Hurricanes jerseys. Sarah has an arm around Amy's shoulders. The photo was taken at Amy's first live rugby game, inside a Hurricanes photo frame with a cartoon Captain Hurricane.



## Upcoming PWSA Events

We hope you have marked our Family Support Camp dates on your calendar for next year! The camp is being held 12-14 March at Carey Park in Auckland. Registrations will be opening later this year.

Registration has just opened for our [Young Families Support Weekend](#), being held at The Surrey Hotel in Auckland, 20 - 22 November 2026. Invitations have been sent to families whose children meet the age criteria. Please get in touch if you need the Trybooking access code resending, or if you have a young child with PWS and haven't received an email. More detailed programme information will be coming soon. You can [register here >](#)

# Disability Support Services Consultation

The DSS consultation closes on **Friday 31 July**. This is an opportunity to have your say on improvements to services and what matters most to you. Disabled people, whānau and carers can take part.



**You are invited...**

**Have your say about disability services**  
Disability Support Services (DSS) is asking for your ideas on how disability services can be improved.

**Share your thoughts and experiences**

- **In-person:** Attend community meetings to kōrero and connect in-person
- **Online:** Join a zoom meeting

Please register online or scan the QR code below to attend in person or online.

**For more information**

- Visit: [disabilitysupport.govt.nz/haveyoursay](https://disabilitysupport.govt.nz/haveyoursay)
- Email: [DSS\\_consultation\\_2026@msd.govt.nz](mailto:DSS_consultation_2026@msd.govt.nz)

**Disability Support Services**

New Zealand Government  
Te Kāwanatanga o Aotearoa

Key areas DSS are consulting on:

- Outcomes that matter - the difference DSS supports can make.
- Planning for life changes - getting the right support at the right time.
- Feedback and complaints - making it easier to speak up.
- Carer respite - improving options for taking a break.
- Flexibility of supports - more choice and control.
- Information and advice - finding and understanding DSS funded supports.

Visit the DSS website for [consultation documents and online survey >](#)

## The Forbidden Pharmacy



**Unlock the medicines New Zealand needs.**

**SHOW YOUR SUPPORT AND VISIT.**

**FORBIDDEN PHARMACY** | **RARE DISORDERS NZ**

SAT - 25.07.26 x SHED 10  
89 QUAY STREET, AUCKLAND CBD  
OPEN TO THE PUBLIC

xxxxxxxxxxxx  
[forbiddenpharmacy.org](https://forbiddenpharmacy.org)

As part of the Rare Disorders NZ collective, we encourage you to consider supporting this initiative. The Forbidden Pharmacy is open for one day only on **Saturday, Shed 10, Quay Street, Auckland 10-5pm**.

Hundreds of medicines remain out of reach for New Zealanders, and this may be the case when more treatments become available for PWS. The Forbidden Pharmacy is a walk-through installation revealing the 200+ medicines New Zealanders can't access.

Go along and see what New Zealanders are being denied, hear the stories behind the medicines and stand with the organisations calling for change.

There are also other ways you can get involved:

- **Friday 24th at Shed 10, from 5 – 9pm - be an extra!** A hero film is being created for the campaign and the crew need as many people as possible.

- **Sign an open letter to all party leaders** when the full [Forbidden Pharmacy](#) campaign website launches on Friday afternoon (24th July). Share the website with your networks, encouraging others to sign.
- **Share your story.** RDNZ are building a [webpage of stories](#) about the impact of not being able to get funded access to a rare disorder medicine. The only medicine specifically for PWS currently on the OFI waitlist is GHT for adults. VYKAT funding can't be applied for until Soleno apply to Medsafe. Parents of young adults may want to share the experience of waiting for GH to be funded in 2009, or the last exclusion criteria being removed in 2016.

Email Angela: [comms@raredisorders.org.nz](mailto:comms@raredisorders.org.nz)

## IPWSO Professional Providers' Forum News

The last forum meeting was on '**Nutrition Structure and Safety in PWS Residential Care Settings**' and took place in May, attended by forum members from New Zealand. You can visit the [Forum Newsletters page](#) to read summary notes, newsletters, and view presentations.

There was really good information presented at the last meeting by Ingrid Hutchinson, RD CORU, Clinical Specialist Dietitian with Resilience support service in Ireland. You can watch the presentation or download the slides from the Forum Newsletters page.



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.



The timing of the next meeting is not so good for us in New Zealand, but if any residential support staff will be up at midnight, the details are below.

Topic: **Medical and Physical Health Needs of Residents with PWS**

Date: **Thursday 24th September**

Time: **Midnight NZST**

To receive the link for this meeting, you need to [join the Caregivers' Forum](#)

# New Resource Alerts



## Understanding Constipation in Prader-Willi Syndrome

This is a useful new resource from PWSA(USA) on the common problem of constipation in PWS.

Low muscle tone and slow gastric motility can contribute to constipation, which can become serious if unmonitored and untreated. Things that may help are encouraging exercise, ensuring adequate water intake, dietary modification, and sometimes medications are needed. Always see a specialist with concerns.

Click here to view and [download](#)>

## Wandersearch Canterbury

WanderSearch Canterbury Charitable Trust is dedicated to safeguarding vulnerable individuals at risk of going missing. They work with all ages and a wide range of diagnoses to supply free radio frequency WandaTrak devices that can be worn by the individual and allow them to be found quickly. The wearer is not being constantly “tracked”- they are only searched for should they go missing.

WanderSearch works in partnership with whanau, carers, and emergency services to provide a proactive response system.

Click here for [more information](#) >



# PWS Research News

## Review of semaglutide (Wegovy) for obesity and hyperphagia

Medicines like Trulicity and Wegovy are being prescribed more frequently. A [small study](#) in the UK recently reviewed the records of 12 patients with PWS treated with semaglutide (Wegovy). They noted improvements in blood sugar control, reductions in hyperphagia, and stabilisation of weight gain, but no significant weight loss. About 25% of patients experienced mild gastrointestinal symptoms. Research is ongoing and larger studies are needed, including trials that further evaluate risk, and trials that include adolescents and adults without diabetes.

## Newly published VYKAT XR data demonstrates meaningful improvements

DCCR / VYKAT™ XR is the first FDA-approved treatment for hyperphagia in Prader-Willi syndrome. It works by opening potassium channels to block overactive neurons (NPY / AgRP) from sending hunger signals. It also reduces insulin releases from the pancreas to help manage fat storage and cue satiety signals.

Individual responses to VYKAT vary and it doesn't work for everyone, but since its approval last year in the USA, more data is emerging on the long-term benefits of treatment. At the annual conference of the Endocrine Society, Endo2026, Soleno Pharmaceuticals shared [three presentations](#) with the complete data from their phase 3 development programme, demonstrating long-term reductions in hyperphagia, behavioural improvements, and positive results when VYKAT was resumed following a 16-week withdrawal period.

As VYKAT becomes more widely used in clinical practice in the USA, some guidance on its use have been [published in the Journal of the Endocrine Society, June edition](#). They include recommendations for patient selection, dosing, and the monitoring of adverse events. Special considerations are discussed for patients with diabetes, cardiopulmonary risk factors, and those on concomitant medications with potential drug–drug interactions.

A side effect seen in approximately one third of patients is hyperglycemia (high blood sugar). This needs to be carefully monitored when treatment first begins. Most side effects have been manageable with dose adjustments. It is recommended that conditions such as diabetes, oedema and sleep apnoea are being managed well before starting treatment to improve safety and tolerability.

## Positive phase 2 data for setmelanotide

Rhythm Pharmaceuticals have released 6-month interim data from a one-year phase 2 trial of higher dose setmelanotide (5mg), given by daily subcutaneous injection. Setmelanotide activates the MC4R receptors in the hypothalamus to promote satiety.

The [results](#) demonstrated consistent BMI reductions with reductions in fat mass, improvement in hyperphagia scores, and improvement in PWS anxious and distress behaviours.

Setmelanotide is already approved in the USA, Europe and the UK under the brand name Imcivree for treating obesity due to acquired hypothalamic obesity (HO), Bardet-Biedl syndrome (BBS), or the genetic conditions of pro-opiomelanocortin (POMC), proprotein convertase subtilisin kexin type 1 (PCSK1), and leptin receptor deficiency (LEPR deficiency).

---

# PWS Research Participation



**RESPONSE TO ANAESTHETIC IN PEOPLE WITH PWS STUDY**

WHO IS ELIGIBLE:

Careers/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 code **KCY7JHAYX**

## 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.

## 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 researchers 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 [watch this video](#) or contact an Asia/ Oceania study representative:

Janet Franklin: [Janet.franklin@health.nsw.gov.au](mailto:Janet.franklin@health.nsw.gov.au), or

Georgina Loughnan: [Georgina.loughnan@pws.org.au](mailto:Georgina.loughnan@pws.org.au)

To access the survey, scan the QR code or [click this link](#) and insert code: KCY7JHAYX

# Transition Expos



**WHAT'S OUTSIDE THE BOX?**

**2026 TRANSITION EXPO**

**SAVE THE DATE**

**10.00AM - 2.00PM**

**THURSDAY 13<sup>TH</sup> AUGUST**

**ĀKAU TANGI SPORTS CENTRE**  
**KILBIRNIE, WELLINGTON**

**What's Outside the Box? Wellington**  
**Transition Expo - Thurs 13th August,**  
**Ākau Tangi Sports Centre,**  
**10am - 2pm**

A list of stallholders and the event programme can be found here:  
[www.well-able.org.nz/page/whats-outside-the-box-transition-expo](http://www.well-able.org.nz/page/whats-outside-the-box-transition-expo)

Check out the Facebook page for updates:  
[www.facebook.com/whatsoutsidetheboxnz](https://www.facebook.com/whatsoutsidetheboxnz)

This free event is proudly brought to you by



# Next Steps



Artwork by Jody

## Next Steps - South Island's Leading Disability Expo

Wondering about the next steps in your disability journey? Explore over 100 disability services, supports and opportunities.

**When:** Tuesday 25<sup>th</sup> August 2026 | 10am - 4pm  
**Where:** Parakiore Recreation Centre  
50 Saint Asaph Street, Christchurch Central

The Next Steps Expo is a friendly space to discover choices for employment, education, housing, recreation, support and more.  
**FREE ENTRY AND PARKING**

Scan the QR code for more info and a list of stallholders:



**aspire**  
canterbury

Proudly supported by  
Christchurch City Council

Enabling Good Lives

WRLG

WRLG

## Next Steps, Christchurch Transition Expo - Tuesday 25th August, Parakiore Recreation and Sport Centre, 10am - 4pm

A list of stallholders can be found here:

[www.aspirecanterbury.org.nz/events/next-steps-2026](http://www.aspirecanterbury.org.nz/events/next-steps-2026)

Check out the Facebook page for more information and updates:

[www.facebook.com/nextstepsexpo](https://www.facebook.com/nextstepsexpo)

|   |                                                                                                          |
|---|----------------------------------------------------------------------------------------------------------|
| A | <b>Transition Coordinators</b><br>Meet a Transition Coordinator to start planning for life after school. |
| B | <b>Government Services</b><br>Information about government services and supports.                        |
| C | <b>IF Hosts</b><br>Learn about managing your disability funding.                                         |
| D | <b>Vocational/Residential</b><br>Explore day programmes, and living options.                             |
| E | <b>University &amp; Education</b><br>Discover study and training opportunities.                          |
| F | <b>Activities and Recreation</b><br>Find social, recreational, and community activities.                 |
| G | <b>Employment/Social Enterprise</b><br>Explore employment and self-employment pathways.                  |
| H | <b>Sensory</b><br>Explore sensory resources, products, and supports.                                     |
| I | <b>Information</b><br>Get advice, information, and support to understand your rights and options.        |

## Auckland Transition Expo - Wednesday 9th September, Auckland Netball Centre, 9am - 2pm

Download a list of stallholders here:

[www.disabilityconnect.org.nz/wp-content/uploads/2026-stallholder-list-for-website-1.pdf](http://www.disabilityconnect.org.nz/wp-content/uploads/2026-stallholder-list-for-website-1.pdf)

Check out the event page for more information and latest updates:

[www.disabilityconnect.org.nz/annual-transition-expo](http://www.disabilityconnect.org.nz/annual-transition-expo)

## Down for Love

### Down for Love is casting

New Zealand's favourite dating show is returning to TVNZ for a fourth series - and we want to hear from you!



Down for Love delivers frank, warm, funny, and heartfelt moments from the quest for love.

If you live with Down syndrome or another intellectual disability and want to dive into the world of dating, get in touch now.

Email [downforlove@reelfactory.tv](mailto:downforlove@reelfactory.tv) to find out more

Down For Love is casting!

If you or someone you know is looking for love, you may want to apply for Down for Love:

[form.jotform.com/261807477841062](https://form.jotform.com/261807477841062)

---

## Dates for Your Diary...

**Forbidden Pharmacy - Saturday 25th July**

**DSS Consultation closes - Friday 31st July**

**What's Outside the Box Expo, Wellington - Thursday 13th August**

**Next Steps Expo, Christchurch - Tuesday 25th August**

**PWRFA Conference, Brisbane - Fri 28th - Sun 30th August**

**Transition Expo, Auckland - Wednesday 9th September**

**IPWSO Caregivers Forum Meeting - Thursday 24th Sept @ midnight**

**PWSA Young Families Support Weekend - Fri 20th Nov - Sun 22nd Nov**

**PWSA Family Support Camp - Fri 12th - Sunday 14th March 2027**

---

*Copyright © 2026 Prader-Willi Syndrome Association NZ Inc.*

### Contact Us:

[www.pws.org.nz](http://www.pws.org.nz) | [enquiries@pws.org.nz](mailto:enquiries@pws.org.nz) | 0800 4 PWS Help