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

March 2023 Newsletter

National PWSA Camp at Lake Taupō

We enjoyed seeing members again after an extended break between camps due to the Covid19 outbreak. We had 72 members join us at camp this year and families enjoyed the opportunity to reconnect and meet new families and individuals. Thank you for the feedback provided by those who attended - we look forward to making camp bigger and better next time! Please see our news post for more camp info and pictures >

Adults Living with PWS Leadership

We held an ALPWS Leadership Meeting at camp which all adults living with PWS were invited to attend. ALPWS Leadership has been established for 5 years and has contributed to the development of resources and training programmes. However, at this year's meeting, it was decided that a representative group will meet more regularly and they have set themselves some goals which include: increased leadership opportunities, offering peer support, organising more social events and connection via Facebook, a spokeperson(s) at PWSA board meetings, fundraising and creating awareness.

Please check out the group's updated web page for more information about ALPWS Leadership >. The group intend to meet monthly via Zoom on the 2nd Monday of each month @7pm. Next meeting will be April 10th.

Rare Disorders Month

During March, RDNZ held Aotearoa's first ever Rare Disorders Month. As part of the RDNZ collective, we were 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 to bring about changes promised.

To mark Rare Disease Day on February 28th and the start of Rare Disorders Month, RDNZ launched a new parent and caregiver guide, '*Raising a Child with a Rare Disorder'.*
We were invited to the launch at Government House, hosted by Her Excellency, The Rt Hon Dame Cindy Kiro. It was a pleasure to meet Her Excellency and we think she enjoyed meeting some of our youngest members too!

This parent and caregiver guide is now available to download from RDNZ's website. A link can also be found on our New Parent Resources page.

Rare Disorders Month events have been held around the country. Grace and mum, Wendy, supported an event held at Warkworth Library (see photo.) They are sporting Rare Disorders Month temporary tattoos, which many of those at camp also received. Free tattoos can still be ordered from RDNZ. There's still time to #GlowUpShowUp!

If you haven't already, please share Rare Disorders Month social media posts, and please watch and share some of RDNZ's videos (below) which explain the need for a National Rare Disorders Strategy. Individually we are rare, together we are many! #DoRightByRare


However, New Zealand's Ministry of Health does not collect data on rare disorders. New Zealand has...

NO definition of what is considered rare

NO official rare disorder data registry


What does it mean to have a rare disorder strategy?


RARE DISORDERS MONTH 2023

GLOW UP AND SHOW UP FOR RARE DISORDERS

#GlowUpShowUp

UNLIKE MOST OECD COUNTRIES, WE DON'T HAVE A RARE DISORDER STRATEGY IN NEW ZEALAND. URGENT ACTION IS NEEDED TO IMPROVE DIAGNOSIS, CARE PATHWAYS, COORDINATED SUPPORTS, AND THE AVAILABILITY OF TREATMENTS FOR THE 300,000 OR MORE PEOPLE LIVING WITH RARE DISORDERS IN NZ.

PRADER-WILLI SYNDROME IS A RARE DISORDER AFFECTING APPROX 1 IN 16,000 NEWBORNS.

PWS IS CAUSED BY RANDOM LOSS OF GENE FUNCTION IN A REGION OF CHROMOSOME 15.

PWS AFFECTS THE HYPOTHALAMUS, A BRAIN ORGAN RESPONSIBLE FOR PRODUCING MANY HORMONES.

PWS SYMPTOMS INCLUDE: LOW MUSCLE TONE, DEVELOPMENTAL DELAYS, HUNGER, ALTERED METABOLISM, LEARNING DISABILITIES, AND BEHAVIOURAL CHALLENGES LINKED TO ANXIETY, RIGIDITY, COMPULSIVITY & EMOTIONAL CONTROL.

PWS
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RARE DISEASE DAY®

RARE DISORDERS NZ

We also have a chance as a community to ensure the rare voice is heard in the development of the new Pae Ora health strategies. Join one of two webinars run by RDNZ and Manatū Hauora – Ministry of Health to share what you want to see changed and what would make the biggest difference to your life and whānau. Discussions continue on the development of a Strategy for Rare Disorders. To date there is an outline plan. Register here>


We want to hear from YOU!

Join one of our webinars to ensure the rare voice is heard in the development of the Pae Ora health strategies:

- Wednesday 29 March 8:00pm – 9:00pm
- Tuesday 4 April 12:00pm – 1:00pm

To register visit
raredisorders.org.nz/about-us/events/

RARE DISORDERS NZ

MANATŪ HAUORA
MINISTRY OF HEALTH

Review of Adult Decision Making Law

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 they consulted on their Preliminary Issues Paper which can be viewed here in many accessible formats: www.huarahi-whakatau.lawcom.govt.nz (capacity.lawcom.govt.nz). The PWSA submitted a response outlining some concerns specific to Prader-Willi syndrome. You can read the PWSA submission here >
There will be a second issues paper, and consultation, later this year.

What's **Welfare Guardianship**?

Why is it important for people with disabilities and their families?

A **Welfare Guardian** is appointed by the Family Court to support the decision making of an adult who is unable to understand the nature and consequences of any decision about their personal care and welfare – this is called lacking capacity.

Capacity is **decision dependent**, so a person may have no trouble understanding some decisions but may lack the capacity to understand others.

It can be important to have a Welfare Guardian in place, particularly if the person lacking capacity has a lot of **medical needs**, or if they are considering moving into a residential or **any other type of residence that requires someone to give consent**.

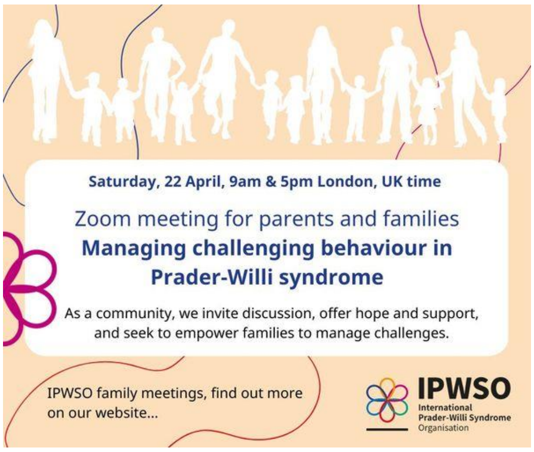
What is Welfare Guardianship? Why is it important for some people with disabilities and their families?

These slides by Nan Jensen, shared with Disability Connect, provide clear information. Nan Jensen is a Barrister and Solicitor specialising in disability law. She regularly presents Planning for Adulthood webinars hosted by Disability Connect.

REMINDER: Parent Zoom Meetings - Managing Challenging Behaviour

These IPWSO family meetings are being held at 2 separate times to accommodate different time zones:
April 22nd 9am = **Sat April 22nd 8pm NZ**
April 22nd 5pm = **Sun April 23rd 4am NZ**

This is one of the most commonly discussed issues in PWS. There will be brief presentations from two professionals and two parents. Meetings are directed at parents and families, but anyone with an interest in PWS is welcome. Registration in advance is essential >



Saturday, 22 April, 9am & 5pm London, UK time

Zoom meeting for parents and families
Managing challenging behaviour in Prader-Willi syndrome

As a community, we invite discussion, offer hope and support, and seek to empower families to manage challenges.

IPWSO family meetings, find out more on our website...

REMINDER: Mental Health ECHO Series

A reminder that IPWSO's Mental Health ECHO® begins tomorrow @ 4am (NZ time). Don't forget to share details (pdf) with any professionals that you are working with.
The Mental Health ECHO aims to build a community of healthcare professionals and caregivers supporting wellbeing and mental health for people with PWS. The series 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.

It is aimed primarily at mental health professionals and professional caregivers; allied health professionals and parents in supportive roles with their national PWS association are also welcome.

Flu Vaccine available from April 1st

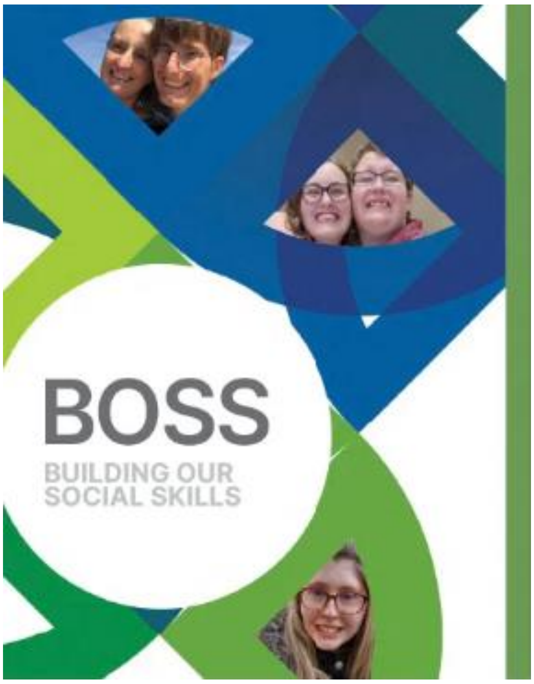
Pharmac has widened access to the annual funded flu vaccine from being available to tamariki from 3 years, to being available from 6 months. The flu vaccine is free for all people who have long-term health conditions, which includes PWS.

Whilst it is thought that those with PWS are not necessarily immune compromised, there may be complications of flu as respiratory weakness is common. Illness is also difficult to monitor and treat in PWS with body temperature irregularities, an altered pain threshold and a possible lack of vomiting.

New Resources Alert: BOSS

The Building Our Social Skills (BOSS) curriculum was developed at Vanderbilt University as part of a grant funded by FPWR. It is a 10 week social skills intervention programme for loneliness reduction in teens and young adults.

The BOSS curriculum can help build skills to read facial expressions, tone of voice, and nonverbal cues. It can also help people try out problem-solving strategies, make new friends and focus on what they can do better. Individuals who completed the BOSS programme (and their parents) noted improvements in social skill abilities, being able to initiate social interactions, and fewer behavioural problems.



Parent or clinicians interested in learning more about the BOSS program can download the Guide for Parents and Clinicians.

Facilitators ready to use the BOSS curriculum can download the 80-page e-book to get started with the programme. The BOSS e-book includes:
- Detailed instructions for all 30 sessions taught during the 10-week BOSS curriculum.
- Tips for facilitators.
- A guide for parents to help reinforce the social skills taught throughout the programme.

More good news for Neuren Pharmaceuticals

Following approval of their planned phase 2 trial of NNZ-2591 in PWS (mentioned in our last newsletter), Melbourne based, Neuren Pharmaceuticals have shared more good news.

The FDA have recently approved Neuren's NZ-discovered drug for Rett Syndrome, a severe neurological disorder for which this is the first approved drug treatment. As it is also the first locally-discovered (University of Auckland) neurological treatment to make it to market, NZ science history has been made. Trofinetide (Daybue), just one of a handful of NZ-discovered drugs to gain FDA approval, is expected to be available in the US very soon, but it is not yet clear when it will be accessible to patients in New Zealand.

The approval of Daybue is also good news for Neuren's drug pipeline, providing essential funding to advance the development of NNZ-2591 for several disorders, including PWS. We have engaged with Neuren regarding future clinical trial opportunities for patients with PWS in New Zealand, but they have confirmed that phase 2 trial sites will be in the USA. However, they do anticipate a larger registration trial after that and will decide the locations for that trial later on.

Board Member Vacancies

Our annual AGM is coming up which is an ideal time for new members to join our Board. We are keen to hear from anyone who has an interest in becoming more involved in the governance of our organisation. If becoming a Board Member is something you might be considering, please feel free to contact us with any questions.

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.

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
Rare Disorders Awareness Month - March
ALPWS Leadership Meeting - April 10th
PWS Awareness Month - May

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 29 March - Auckland - 10am to 4pm

Click here for more information >
To register, please email: ihc.events@ihc.org.nz

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.