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

February 2024 Newsletter

It's Rare Disease Day!

We are rare! PWS is a complex syndrome that is sometimes not well understood by health, disability and support systems, and it is therefore important that we unite with other rare disorder groups to improve health outcomes and support for people living with rare disorders.
Rare Disease Day is also the start of Rare Disorders Month in Aotearoa New Zealand. Please join RDNZ to #GlowUpShowUp during March.

Last night, RDNZ launched their 'Impact of Living with a Rare Disorder' white paper at Parliament. Attendees included Minister of Health Hon. Shane Reti, the Minister for Pharmac Hon. David Seymour, the Minister of Mental Health Hon. Matt Doocey, as well as researchers and health professionals. The white paper is based on the 2023 rare disorders survey which many of you may have participated in. Click here to view or download the white paper >
You may also have seen media articles about RDNZ's work with the Ministry of Health to develop a much needed rare disorders health strategy and their campaign for the establishment of a Centre of Expertise. We believe these are urgently required to improve the health and wellbeing of people living with PWS. Please support Rare Disorders NZ and help share important messages explaining needs.

Save The Date!

The 6th Asia Pacific PWS Conference is being held in Sydney, 30-31 August 2024. This will be a 2 day conference incorporating both a scientific research focused day, plus sessions for healthcare professionals, those working in a support role for people living with PWS, and for parents and caregivers. This year, the conference is a 'hybrid' event, being held both in-person and online. Attendees will be able to register for either option.

Discover Care Thrive

6TH ASIA PACIFIC

PRADER-WILLI SYNDROME CONFERENCE

30TH - 31ST AUGUST 2024
SYDNEY, AUSTRALIA

The latest in research and care for researchers, clinicians, families and people with support roles, including hearing from people with PWS.

FEATURED SPEAKERS

NEURO-BEHAVIORAL MANIFESTATIONS OF PRADER-WILLI SYNDROME

CHECK OUT DR. SINGH'S NEW BOOK!

Dr. Deepan Singh
Psychiatrist and author of Neuro-behavioural Manifestations of Prader-Willi Syndrome

Prof. Tony Holland
President, IPWSO

An Asia-Pacific PWS collaborative initiative to change life with PWS, brought to you by:

PWSA Prader-Willi Syndrome Australia

PRADER-WILLI RESEARCH FOUNDATION AUSTRALIA

PWS PRADER-WILLI SYNDROME ASSOCIATION NEW ZEALAND

PRADER - WILLI SYNDROME MALAYSIA

Growth with love PWS THAILAND

We encourage anyone to attend who wants to learn more about Prader-Willi syndrome, including the latest in research, treatments, and care guidelines. This conference provides an excellent opportunity to connect with researchers, clinical experts, allied health professionals, and those working to support people living with PWS, from around our region and internationally. For professionals and support agencies it provides an opportunity to share expertise with others in the health and disability support sectors.

PWSA Education Survey closing......

This is a last chance to complete our survey if you haven't done so already. The purpose of our survey was to gather data and information about school supports received or declined, in particular ORS and SHHNF. We intend to use this data to help us advocate for better funding for pupils, and for funding specifically targeted at ensuring health and safety in PWS. Survey Link: https://forms.gle/gxCt6VCugJWKD6QVA

Medicines Wishlist?

There is much hope that some of the medicines in final trial stages and close to being approved overseas will be readily available future treatments for people living with PWS, i.e. carbetocin and DCCR.
However, there are some medicines already available overseas which are sometimes used to treat particular symptoms of PWS, but they are either not available here, or are only available via section 29 of the Medicines Act (for unapproved medicines).

PHARMAC are currently requesting applications for medicines for rare disorders and we intend to apply for guanfacine, pitolisant and for the availability of pharmacogenomic gene testing for psychiatric medicines. Are you interested in guanfacine or pitolisant? Are there any other medicines on your wishlist? Please get in touch with jo.davies@pws.org.nz before March 6th.

Growth Hormone Funding for Adults Approved

After many years of arguing the case for the continuation of growth hormone treatment through adolescence and adulthood, its funding has finally been approved! However, whilst it is approved for funding, it remains unfunded on Pharmac's Options for Investment List which was updated in January. We will continue to ask about when it might be funded and are hopeful that future increases to government funding of Pharmac and the minimal comparative cost of GH for adults will accelerate the wait for funding.
When funding is available, the endocrinology advisory committee have proposed that GHT will be available on the basis of a PWS diagnosis alone with the usual exclusion criteria of diabetes or uncontrolled obesity.

Advocacy Updates

Scoliosis Radiographic Screening Programme

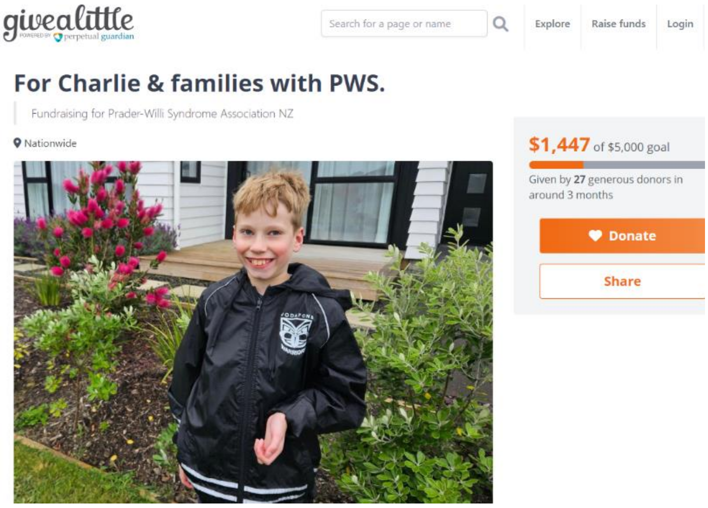
Following concerns about late diagnosis of scoliosis in some patients with PWS, we sought the advice of international expert Dr Harold van Bosse, and have written to New Zealand's orthopaedic, endocrine and paediatric groups to request a review and the implementation of a screening programme in New Zealand similar to that described by Dr van Bosse, who has very kindly offered to be available for any questions regarding his practice or experience. We have received acknowledgement of our letter and will keep you updated with any response. Early identification of spinal curves are very important for preventing a future need for surgery. Dr van Bosse screens annually from when infants are sitting unassisted until 4 years old and successfully treats many young children with casting.
Click here to read our request >

Update on Oral Testosterone

In our last newsletter, we reported that we had provided feedback to Pharmac on their proposal to award Principal Supply Status to Testagel. Our submission requested that a tablet / capsule form of testosterone be made available to new patients starting testosterone treatment.

There have been no changes to the current formulations of testosterone available following consultation, but Pharmac offered this response: "Unfortunately, we were unable to secure a Medsafe approved testosterone capsule product from this procurement process. We will continue to explore options that could address an unmet health need for people requiring testosterone."

Paris Marathon Fundraising



For Charlie & families with PWS.

Fundraising for Prader-Willi Syndrome Association NZ

Nationwide

$1,447 of $5,000 goal

Given by 27 generous donors in around 3 months

Please support Craig James and share his fundraising page as he prepares to run the Paris Marathon in April.

Amazing Craig is a work colleague to young Charlie's dad and has kindly decided to raise funds for the New Zealand PWS Association.

Craig's Givealittle page >

Notices / Events

Dates for your Diary

PWS Awareness Month - May 2024

Next Asia Pacific PWS Conference, Sydney - 30th-31st August, 2024

Next IPWSO Conference - USA, 2025!

Show Your Ability

Annual Disability Equipment Expo 2024

CHRISTCHURCH - TUES 9TH APRIL - Pioneer Rec & Sport Centre

DUNEDIN - WEDS 10TH APRIL - Edgar Stadium

More details here >

Flyer here >

StarJam Online

As StarJam continues to grow and there are sometimes waitlists, they have looked at ways of reaching out to more people and engaging new Jammers. Two new online workshops have begun this year:
Screen Superstars - 6 - 7.30pm Thursdays
Online Sensations - 4 - 5.30pm Thursdays
Click here to complete an online expression of interest >
StarJam website >

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.