

November 2022 Newsletter

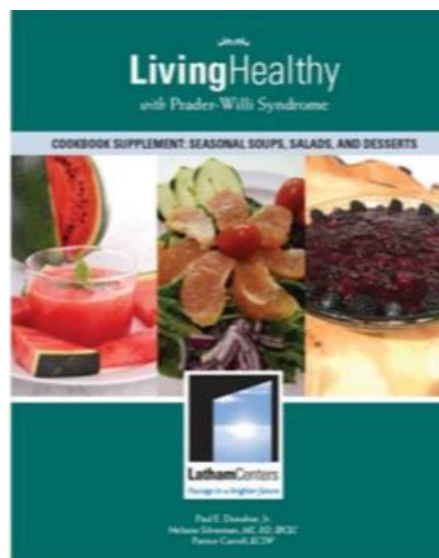
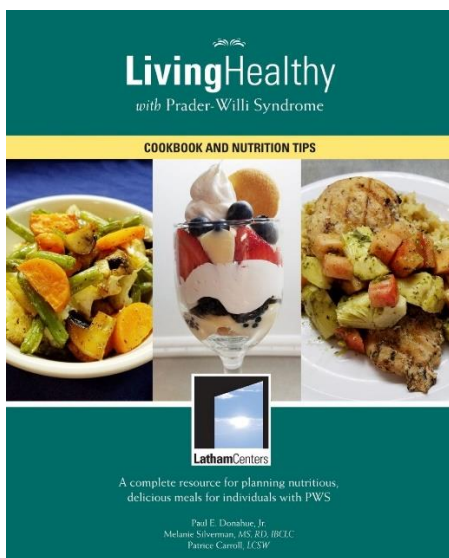
Camp Registrations and Payments

Good news - we have 25 group registrations and over 90 people registered for [camp](#) next year! We are reviewing numbers and considering if we will need to close registrations at some point. If you have registered, but have not yet sent your confirmation payment, we would like to remind you to secure your place as soon as possible. Please [get in touch](#) if you have any difficulties with this or would like us to resend payment details. We would also like to remind those booking flights to send through your booking receipt for subsidy payments. Our camp is for people living with PWS of all ages to attend with their family or a support worker. Registration is via our [online form](#).

Christmas Gift Ideas!

We have exciting news that we will soon have cookbooks available to purchase! These [cookbooks](#) were produced for people living with PWS by Latham Centers (a PWS specialist service provider in the USA) and are co-authored by internationally renowned PWS expert dietitian, Melanie Silverman. We are very much hoping that we will be able to start sending these out before Christmas and will start taking orders once we have a date from our printers.

The books are normally available to order from Latham Centers for around NZD80.75 and NZD40. However, we have been granted permission to print them here in New Zealand, which will mean a very substantial cost saving per book for families and service providers.



Are you looking for further meaningful gift ideas? Check out www.specialgifts.co.nz, a new platform that supports entrepreneurs and companies which are run by or employ people with disabilities, by selling their products in attractive eco-friendly gift boxes.

Getting Ready for the New School Year



Prader-Willi Syndrome Association NZ



Teachers' Pack



With the end of school year approaching, if you would like to order our free Teachers' Packs for your child's new teacher, syndicate or school, please send us an [email](#) or use our [resource order form](#). Packs will be posted out in December and again from mid-January.

Alongside other resources, an online version of our Teachers' Pack can also be downloaded from our [resources page](#).

A reminder that we are able to offer free school training when needed (available via Zoom) - please see [Training Workshop 4](#) for details.

Special Olympics Nationals

Good luck to all the athletes competing in the Special Olympics National Summer Games in Hamilton! We would love to know how you get on - please send us any pictures and updates and we will be happy to share them. A reminder that if you are participating and would like to meet up with other athletes living with PWS, please [contact us](#) and let us know which sport you are competing in.



National Summer Games
Hamilton 2021

Growth Hormone Access

Growth hormone treatment is currently funded for all children with PWS via Special Authority from 6 months to end of growth (females 14 years / males 16 years). An endocrinologist needs to initiate the subsidy and this must be renewed by an endocrinologist every 12 months. A patient's GP (or authorised prescriber – which could be a Nurse Practitioner if this is within their scope of practice) is able to prescribe somatropin in between visits with the specialist.

Once end of growth is reached, there are 4 ways in which GHT can continue:

1. A patient is tested for growth hormone deficiency and meets the deficiency criteria.
2. A patient's specialist submits a successful [NPPA](#) (Named Patient Pharmaceutical Assessment) to Pharmac.
3. A patient or their 'agent' can apply to WINZ to try and cover the cost through Disability Allowance after collecting 6 months of receipts.
4. The treatment is self-funded.

We are trying to gather more detail about 2 and 3 above. If you have been successful in obtaining funded GHT via either of these ways, we would be keen to hear from you. Similarly, if an NPPA was declined, or you applied to WINZ unsuccessfully, we would also like to hear from you. Please [contact us](#) with further details.

If you have questions about any of the above, please [contact us](#) for further information.



Rare Disorders Hui

On Friday 11th November, Jo and Charlotte attended a one-day hui in Wellington for rare disorder support group leads. The hui provided an opportunity for discussing common barriers and the importance of combined advocacy with others in the rare disorder community. The agenda included a session with HDC and

HQSC to learn more about health consumer rights. We also heard inspirational success stories shared by three support groups and the day ended with discussion around advocacy focus areas for the year ahead and Rare Disease Day 2023. With an upcoming general election, it will be important that we raise awareness of key issues with effective messaging around these. Key issues were agreed to be ensuring input into the design of the National Strategy for Rare Disorders within Te Whatu Ora / Health New Zealand policy, improved data collection on rare disorders, and equity in Pharmac decision making with increased funding of medicines. If you have any ideas for RD Day (Feb 28th), please [get in touch!](#) We would like to give special thanks to Rare Disorders New Zealand for hosting the hui.

Royal Commission of Inquiry into Abuse in Care

What can be done to improve care and support services for those with disabilities or experiencing mental distress? **Until 15 December**, the Royal Commission of Inquiry into Historical Abuse in Care invites you to share thoughts to their ideas wall through the online platform: www.korero.abuseincare.org.nz. This online engagement provides a way for people to share ideas, but individuals and their whānau are also welcome to engage with the inquiry through private sessions or statements. Those with

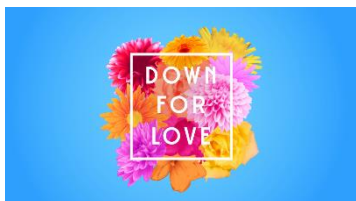
Contribute to our **Ideas Wall**. Tell us how services and support can be improved for people who are disabled, Deaf, neurodiverse, whānau hauā, whaikaha, tāngata Turi, tāngata whaiora, or experience mental distress.

 Abuse in Care
Royal Commission of Inquiry

experience of abuse or neglect are able to make contact by phone, email or text so that experiences can be shared in a way that works best for them. Phone 0800 222 727 (weekdays 8.30am - 4.30pm), text 8185, or email: contact@abuseincare.org.nz (include a phone number and a time to call.) Neglect may include culture and identity not being respected, mana and dignity not being upheld, being unable to access support etc. Click here to view [further information](#) about the inquiry. An [Easy Read pdf](#) is also available.

Highest Educational Needs Review Outcome

Earlier this month, the government announced its plans to [overhaul](#) the special education system following feedback from the Highest Needs Review. The [change programme](#) includes plans to shift away from the ORS application-based system to a simplified funding model where schools will be able to provide more flexible supports according to individual pupil need. This will be welcome news to those currently experiencing barriers to accessing learning support, but whilst we are hopeful these proposed changes will be developed now there is government acceptance that so many pupils are missing out on learning support, the details of the overhaul are yet to be announced and change is dependent on significant [budgetary input](#). Click here to read the findings and recommendations in the [Highest Needs Review Report to Cabinet](#). The PWSA(NZ) were one of many contributors to the review.



Casting Call Reminder!

Attitude TV is casting '[Down for Love](#)' Season 2, a series on TVNZ 2 produced in consultation with NZDSA which focuses on people living with Down Syndrome and other intellectual disabilities as they explore dating.

Attitude Pictures would love to hear from those aged 18+ who are looking for romance and want to explore local dating options or learn the tools to woo a future partner. Complete this [form to apply](#) or contact Daniella to find out more: daniella@attitudepictures.com

Advent Calendars & PWS

Today marks the beginning of advent and for many, the day when advent calendars are first opened, typically containing chocolates. Check out this post by PWSA Ireland if you are looking for [chocolate-free calendar](#) ideas.

Sibling Resources

Now that in-person gatherings are happening again, the SibShops run by Parent to Parent are back up and running. Keep an eye out for events near you - there is a surf day coming up at Ohope Beach, Bay of Plenty on Dec 4th and canoeing at Kaiteriteri Dec 20th!

There are some new sibling resources which have become available recently - links to useful resources can be found on our [siblings page](#). One new resource we can highly recommend is this [video](#) in which Gina O'Brien discusses her experiences growing up as a sibling of a person living with PWS, a part of IPWSO's Leadership ECHO series.



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.

Double your Impact on Research (until Dec 15th)

The Foundation for Prader-Willi Research have another matching offer thanks to a generous donor doubling all donations up to \$400,000. [Double your donation dollars here!](#)

Notices / Events

Dates for your Diary

Virtual Social Evening for Parents of 0-5 Years - Sun 11th December, 7.30pm
Virtual Social Evening for Parents of Teens/Adults - Sun 29th January, 7.30pm
PWSA(NZ) Family Camp - 10th-12th March 2023

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.