

## December 2022 Newsletter



As the year draws to a close, we reflect on highlights of the year that's passed. During 2022, we produced a selection of new resources, we were able to hold another in-person, age-focused event and are looking forward to what will possibly be our biggest ever family camp in March! We have also been able to continue our on-site training programme this year - please get in touch if you would like to [book training](#) (on-site or online) for 2023.

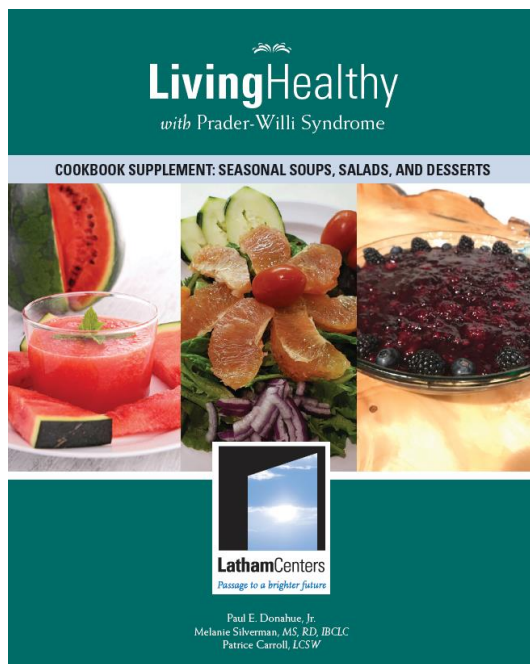
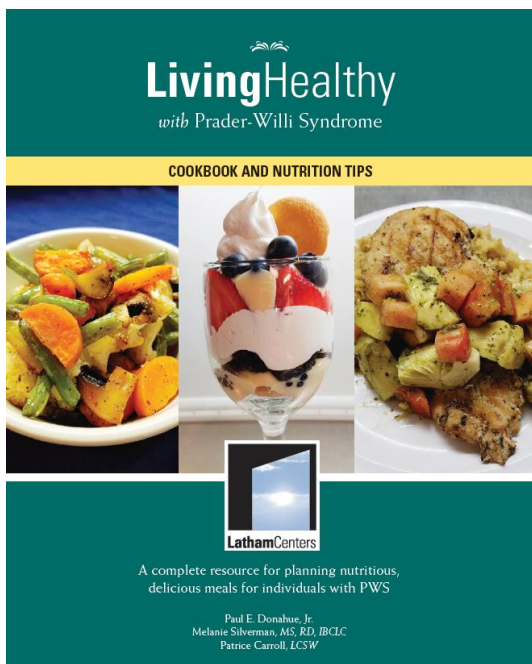
2022 has also been a year of positive developments in the health and disability sectors. The Government finally committed to developing a National Strategy for Rare Disorders, the Pharmac Review recognised a lack of equity in Pharmac's decision making, a new Ministry of Disabled People, Whaikaha, was launched, the Highest Needs Review established the need for an overhaul of the special education system so that the those with the highest learning needs are better supported, and the increased flexibility approach for Carer Support and IF, which began as part of the Covid-19 response, was made permanent.

PWSA staff will all be taking a break over the Christmas period, but are still available for any urgent enquiries or support. We will be back to normal service again from January 16th. We would like to thank all our members for your continued support and look forward to bringing you new events and resources in 2023. We wish you all a healthy and happy holiday season with our best wishes for the New Year.

## Resources Orders

Thank you to everyone who ordered the new [cookbooks](#) by Latham Centers before December 14th. These were sent out via a tracked service, so please let us know if they have not arrived. Any [late or new orders](#) will be sent out after the Christmas and New Year break. Cookbooks will also be available to purchase at our upcoming Family Camp.

Teachers' Packs were also sent out earlier in December. If you would still like to [order a Teachers' Pack](#) for next year, we will be able to post more out so that they are received before the end of January. Please order by Wednesday 18th January to be sure of receiving a pack before the start of the new school year.



## Special Olympics Nationals

Congratulations to all the athletes who participated in the torch relay and competed in the Special Olympics National Summer Games in Hamilton!  
Here are some pictures of some of our member athletes:



## Getting Through the Holidays

As we all prepare for the holiday season, here are [some tips](#) to help reduce anxiety for individuals living with PWS and their families.

## Rare Disease Day/Month - Feb 28th & March 2023

As part of the RDNZ Collective, we'd like to share their [volunteer survey](#). Your help is needed to make Rare Disease Day 2023 bigger than ever, to raise awareness of the challenges faced by those living with rare disorders, and to help maintain pressure on our government (especially in an election year) to bring about changes promised. Are you able to ask a school or business for support?

## 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 an adult's decision-making is affected. They want to hear your experiences and views on how the law could be improved.

To learn more about the review, to have your say, or to join the next webinar (Fri 20 Jan 12:30pm-1:15pm), visit [www.huarahi-whakatau.lawcom.govt.nz](http://www.huarahi-whakatau.lawcom.govt.nz).

Submissions close at 5pm on 3 March 2023.

## 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](mailto:ceo@pws.org.nz).

## Pharmac Review of Rule 8.1b - Petition

Rule 8.1b allows the funding of all medicines to treat children with cancer without needing an evaluation by Pharmac first. This exception to the usual funding process is being reviewed due to concerns around the increasing cost of new medicines and because there are equity issues as a result of children with other rare disorders not having the same funding access to life-saving medicines.

There are concerns that the review could lead to a reduction in access to child cancer medicines. Patient Voice Aotearoa started a petition to oppose this option and urging Pharmac to improve equity by extending rule 8.1b to all New Zealand children living with illness. PVA and RDNZ presented this petition to Parliament on Dec 14th, but you are still able to [sign here](#). Pharmac is seeking feedback until 5pm on 31 January 2023. If you would like to make a submission, you can [submit here](#).

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# 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. We would like to discuss ideas for the format of these meetings with those attending the [Adults Living with PWS Leadership Group](#) meeting at our 2023 camp. If you are not attending camp, but would like to contribute, please click here to [send us ideas](#).

Our virtual social evenings for parents continue for now, but we are also reviewing these and plan to make changes in time. We are hoping to host meetings that are more discussion topic based, but we will still have some age specific meetings.

## Dates for your Diary

**Virtual Social Evening for Parents of Teens/Adults** - Sun 29th January, 7.30pm

**Virtual Social Evening for Parents of 6-12 years** - Sun 26th February, 7.30pm

**PWSA(NZ) Family Camp** - 10th-12th March 2023

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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.