



December Newsletter

We would like to wish you all happy holidays! We hope you are able to enjoy a fun, safe and relaxing Christmas break. Here are some useful [holiday tips](#) from PWSA(USA) and here is a useful reminder [letter](#) for family and friends about caring for someone with PWS.



Dane and Julia interview Dr Miller at IPWSO Conference

Julia and Dane Fuller were one of the New Zealand families who attended the IPWSO conference in Cuba in November. They were very fortunate to be able to interview highly regarded endocrinologist and PWS expert, Dr Jennifer Miller. You can [view their interview here](#). Thank you Dane and Julia for sharing this.

Congratulations Aaron Bruce!

Aaron Bruce lives in Auckland and has worked at St Lukes Countdown for 25 years. His job originally was to look after the shopping trolleys and now he cleans the staff room. His long service was recently celebrated at a luncheon where he was presented with this certificate. Aaron is rightfully proud of his achievement. He says he enjoys his job and and loves going to work.

If you have anything you want to celebrate in our newsletter, please send us your stories. We would love to share them.





Stick People Pictures Reminder!

A reminder that if you would like to help Paul and Emma Doidge decorate their tour bus, please send us a stick people portrait representing your family. Anyone can draw the picture, just ensure the lines are bold and black and take a photo with your phone. Ideally they would like hands to be linked around the bus, symbolising us all in this together - please see the suggestion.

Paul, Emma and family will be travelling NZ next year raising PWS awareness and funds for research. They hope to meet other families affected by PWS on the way and to share their journey with the world via their blog. Read more here: vagabondfamily.nz and use their [contact page](#) if you would like to catch up with them on their travels.

PWSA News

PWSA(NZ) Survey Reminder

Thank you to those who have already taken the time to complete our survey. Your responses are very useful to our future planning. We last surveyed members 5 years ago and would like to know how we are progressing. Over the holidays we hope you will be able to spare a short amount of time to complete our 2019 survey which will remain open until Monday 10th February. The survey is **completely anonymous** and we estimate it will take up to 10 minutes, or more, depending on how much you write. Survey topics are: events, information, training, conferences, advocacy, communications, awareness and fundraising. Please use this link: <https://forms.gle/JQL4P4Jbmzuv2riM7>



Camp 2020 - registration extended

February 28th - March 1st, Taupo

Registration has been reopened and extended until **Friday 31st January** or until a time prior when the camp becomes full. We have already received a large number of registrations with a good mix of both adults and children with PWS attending. [MiCamp Taupo](#) is a lovely, family friendly camp with accommodation in lodges and small rooms. Camp details and updates can be found on our website [events page](#). Please register using our [online form](#).

Training and Support Opportunity for Christchurch

We recently advertised a PWS training day in December to families and service providers in the Canterbury region. Unfortunately this had to be postponed, but the [confirmed training day](#) is likely to be rearranged for the end of January. Other service providers are encouraged to take advantage of this opportunity and let us know your training requirements. Whilst facilitating training in Canterbury, Cindy would also be keen to visit some of our adults with PWS around Christchurch and perhaps organise a get-together for them. Cindy is also available for any other family support. Please [get in touch](#) if keen.



Prader-Willi Syndrome Association NZ



Teachers' Pack



Resource Pack Orders for 2020

Teacher Packs have been sent to those who ordered them for their new teacher or new school next year. If you would still like to order a Teachers' Pack, we will be able to send these out in January after the Christmas break. You can order a pack by replying to this email or by using the [order form](#) on our website. We are also planning our training schedule for the year ahead. Please let us know if your school requires or would be interested in PWS training.

Recently, we have also been busy sending multiple New Parent Packs to hospitals and genetic services around New Zealand. We have provided these to hospitals before, but it was pleasing to see hospitals proactively re-ordering these following a reminder.

[Missed our last newsletter? Past newsletters can be found here...](#)

Linda Thornton's Retirement from IPWSO

We would like to wish Linda Thornton a happy retirement as she leaves her role at IPWSO and to thank Linda for her long-standing efforts for the international PWS community. Linda was the founder of the New Zealand PWS Association and the National Director until 2011. You can read more about Linda's work in this [article](#) by Georgina Loughnan.

New Zealand Disability News and Useful Resources

* The Ministry of Social Development has released a draft Disability Employment Action Plan for consultation. There is opportunity to submit feedback until Friday 21 February via online survey, email, post or by attending a workshop in one of the main centres (see below.) Click [here](#) to read the media release, action plan or summary document and to provide feedback.

* If you use carer support forms and often have to wait for another form whilst payment is being

processed, you can now click here to [download carer support forms](#).

* Looking for carers or support workers? Some useful websites are [e-Mploy](#) by Manawanui and [MyCare](#).

* Another useful website is [Firstport](#) if looking for disability information in New Zealand.

* Here is a new app that might be worth checking out: [HelpA](#) is a digital health app that allows you to easily keep records, track progress and share information.

Dates for your Diary

Family Camp Taupo - Friday 28th February - Sunday 1st March

Rare Disease Day 2020 - Saturday 29th February

Regional Notices / Events

NZDSN National Symposium 'Transition from School'

Wednesday 25th March 2020, 9am - 4pm, Rotorua

This may be of interest to professionals. Cost \$150 +gst.

An opportunity to hear about developments from around NZ showcasing effective practice and promising approaches. Click for [further details and registration](#).

Draft Disability Employment Action Plan Consultation workshops.

January 29th Wgtn, 30th Auckland, 31st Christchurch

NZDSN has been asked by MSD to host a series of half day workshops to get feedback from providers on this action plan. This is an opportunity to discuss the contents and proposed actions in the draft, and to offer input into how the plan can ensure the best employment outcomes for disabled people. Click here for workshop [details and registration](#). View the action plan '[Working Matters](#)' here. Summary documents and online feedback links can be found [here](#).

[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.