



## June Newsletter

We have had a busy year so far with our new CEO, Charlotte Roos, taking over from Sarah McLarin, a Teens Weekend in May, regional events in Wellington and Christchurch, plus PWS Awareness Month. We are still looking for someone to help coordinate events for Auckland - please let us know if you would be interested. This mainly involves being the point of contact for a family day event. Please contact [ceo@pws.org.nz](mailto:ceo@pws.org.nz) for further details and to ask any questions.

### Teens Weekend News

We recently held another teens weekend, this time in Wellington. Our programme included lots of sight-seeing around our capital city, including visits to 2 museums, the Carter Observatory, riding the Wellington Cable Car and the waterfront croc bikes. There was plenty of social time for both teens and parents and both groups really enjoyed making these connections. [Read more here >](#)



### Upcoming PWSA Events

#### Young Families Weekend

A reminder that this weekend is taking place in Christchurch, Nov 1st - 3rd. Details are listed on our website [events page](#). There is still more accommodation available at this stage - please register if you are keen.



#### Family Camp 2020 - Save the date!

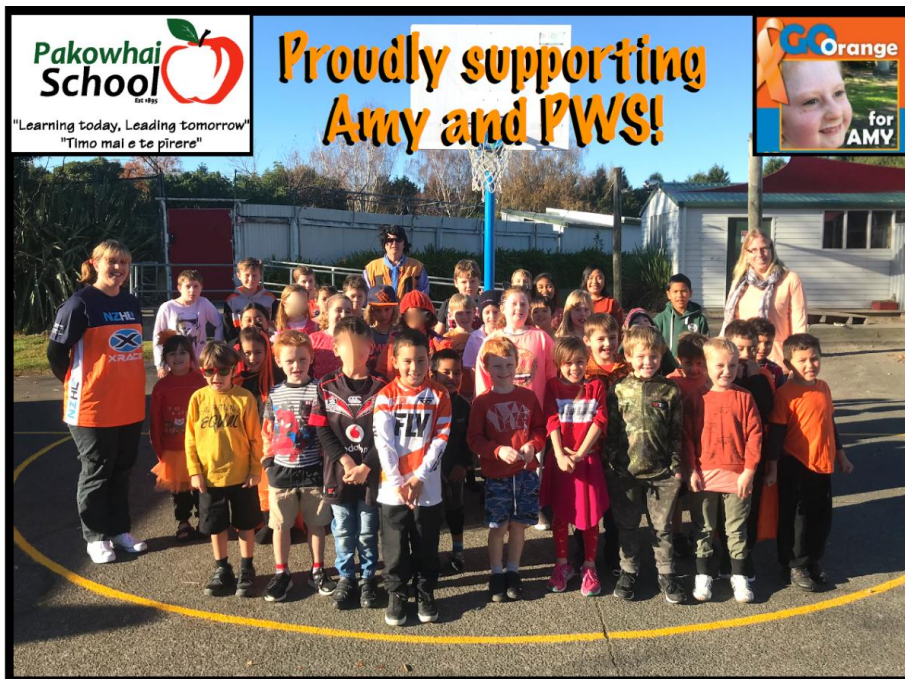
Next year we are holding a summer camp at MiCamp Taupo. Please save the date: Friday February 28th to Sunday March 1st. We will be taking registrations and deposits for camp nearer the end of the year. Flight or ferry subsidies will be available for those travelling from the South Island – amount to be confirmed – you may wish to take advantage of any flight sales in the meantime. Please contact us with any questions.



Please check our [events page](#) every now and then for PWSA event details and other events of interest.

## PWS Awareness Month of May

Thank you to everyone who helped spread some PWS awareness during May. This could be from sharing some of our daily awareness posts on Facebook to wearing ribbons and wristbands to organising a Go Orange Day awareness event at your school or workplace. Here are some pictures of Kiwi families Going Orange this year.



## Update: Growth Hormone Therapy for Adults

Thank you to all the families who have sent us your observations regarding the effect on your child when GH treatment was ceased or restarted. Please keep sending us this information, plus any other evidence, such as copies of relevant sections of clinic letters, teacher observations etc. We also appreciate receiving information about adult endocrinologists and the cost of self-funding treatment because this is useful information to share with other families.

The good news is that self-funding GH therapy for adults appears to be less expensive than we initially expected. There does appear to be variation in price paid, but costs seem to be between \$62 - \$83 per month for a maintenance dose.

[Read more](#) about self-funding GH treatment and the information that would be useful to us.

[Read More: Growth Hormone Therapy for PWS](#)

## PATH for PWS - Last chance to sign up

There's still time to join more than 600 families who have enrolled in the PATH for PWS study! This 4-year, survey-based study will advance knowledge of serious medical events in PWS and will help researchers understand how PWS-related behaviours change over time. If your loved one with PWS is age 5 years or older, please consider enrolling.

**A good number of New Zealand families participating would also mean we are more likely to be invited to take part in future clinical trials.** Enrollment will close June 30th, so enroll today!

Participants will receive a \$100 e-gift card for completing the initial surveys, \$100 for participating in the optional d-dimer sub-study, and \$50 for completing the follow-up surveys every 6 months!

Visit [www.PATHforPWS.com](http://www.PATHforPWS.com) or contact [info@PATHforPWS.com](mailto:info@PATHforPWS.com) with questions.

## PWS Training for Service Providers

We have run a couple of training courses already this year but don't have any current bookings. If you are interested in some PWS training, we are able to offer one day workshops for a small fee of \$60 per person as a contribution toward covering our costs.

Please see our [training page](#) and complete a training request form if you would like to enquire or make a booking. We look forward to hearing from you!

### Dates for your Diary

Christchurch Family Day - 15th June

Transition Expo Auckland - 3rd September

Young Families Weekend, Christchurch - 1st-3rd November

Family Camp Taupo - 28th February-1st March



# Regional Notices / Events

## **Anxiety Workshops - Rotorua, BOP, Hamilton**

Weds 19th, Thurs 20th, Fri 21st June

Free workshops on anxiety to help you recognise and understand feelings of anxiousness, the effect it can have, plan your supports and learn the relationship between depression and anxiety and autism and anxiety.

[View details and register >](#)

## **Wham! Starjam's Superhero Disco - Auckland**

Friday 28th June, 6.30pm - 8.30pm

Western Springs. Gold coin donation on entry.

[View flier >](#)

## **NZ Certificate in Skills for Living for Supported Learners - Auckland**

July intake. Offered by MIT. A fees free programme which runs for 18 months. For people with learning and/or intellectual disabilities who could benefit from developing more independent living skills. Focus on developing these skills at home, work and in the community. Contact Cushla 0211200862 or [Apply here >](#)

## **A Bunch of Mates - National**

Mon 26th - Fri 30th August, 9.30am - 3pm

An interesting new workshop offered by Imagine Better exploring how to build peer networks that also 'transition' into adult life. It also explores how a peer network was leveraged to create real work opportunities. Intended to be practical, honest and with time for open dialogue and questions.

AUCKLAND - August 26th

TE PUKE - August 27th

WELLINGTON - August 28th

DUNEDIN - August 30th

[View details and register >](#)

## **Transition Expo - Auckland**

Tues 3rd September, 9am - 2pm

This Transition Expo features most of Auckland's Transition and Vocational Programme Providers as well as an array of leisure, recreation, sports and information providers. It also features a Transition Seminar in a separate presentation room at 10.30am (1.5hr seminar). If you want to find out more about post-school options, supports, funding and possible living arrangements, this is for you!

This Expo is suitable for all students aged between 14-21 years who are ORS funded, parents, family members, caregivers, education experts, careers advisors, school transition coordinators, teachers and all those involved in the care of a young adult with a disability.

[More info >](#)

## **Interact 2019! - Auckland**

Weds 23rd - Friday 25th October

Groups and individuals are invited to be involved in Interact 2019 at Corbans Estate, Henderson.

This festival celebrates the creative work and achievements of people with a disability and is welcoming to all who want to participate. Complete an expression of interest form even if not sure what you want to present and you will be sent information about the festival. Looking for performers, presenters, workshop leaders, artists.

Form link [here](#). Click to [view flier >](#)

[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 Support

[Parent to Parent branches for local support group meetings](#)

[Sibling Support Programmes](#) - SibShops and SibCamps - these are advertised on the both the Care Matters and Parent to Parent calendars.