



August Newsletter



Young Families Weekend - soon!

Nov 1st - 3rd, Top 10 Christchurch

Registered families will be sent further details soon. We are very keen to encourage some of our newer members to come along as this is an ideal first event, only held every 2 years currently.

Information can be found on our website [events page](#). Let us know as soon as possible if you are interested so we can book any remaining accommodation.



Family Camp 2020 - Save the date!

February 28th - March 1st, Taupo

Next year we are holding a summer camp weekend at MiCamp Taupo. Please save the date! All are welcome. An email containing camp details will be sent out soon - registrations and deposits will be required by the end of the year. Flight or ferry subsidies will be available for those travelling from the South Island – amount to be confirmed soon.

We are still looking for a volunteer to help coordinate social 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 for further details.

Transition Expo - Auckland, Tues 3rd Sept.

We highly recommend this event which features most of Auckland's Transition and Vocational Programme Providers as well as leisure, recreation, sports and information providers. It also features a seminar on transition in a presentation room at 10.30am (1.5hrs). Find out more about post-school options, supports, funding and possible living arrangements.

This Expo is suitable for all 14+, parents, family members, caregivers, careers advisors, transition coordinators, teachers and all those involved in the care of a young adult with a disability. [More info >](#)



transition expo

Explore what is available

03 SEPTEMBER 2019

TIME: 9am – 2pm
VENUE: Auckland Netball Centre, 7 Allison Fergusson Drive, St. Johns

Interactive Activities:

- Opportunities and advice from Transition, Vocational, Recreational and Information providers
- Transition Seminar (10.30 am) covering post-school options, OPE, Work and Income, Supported Living, Individualised Funding, needs assessments
- Drumming, Dancing, Mixed Ability Sports, Pet Therapy
- Competition with Prizes
- Cafe on Site

Additional Information:

- Free Parking
- Wheelchair accessible
- All students with a disability and those involved in the disability sector will enjoy this day.

For more information visit our website
disabilityconnect.org.nz

Contact Details:
website: disabilityconnect.org.nz
email: admin@disabilityconnect.org.nz
phone: 09 6362351
facebook: [PlannedFamilyResourceCentre](https://www.facebook.com/PlannedFamilyResourceCentre)
Supported by: Ministry of Social Development

disability connect.
helping families

Research News

Individuals with PWS who present with challenging behaviours and require medication often have to trial a variety of different anxiety and anti-psychotic medications before the most appropriate drug, dose or combination are found. This can be very frustrating due to the length of time it can take for treatments to take effect and for wash-out periods in between. Success can also be somewhat limited by the treatments that are available. Therefore, it is reassuring to know that a medication for a new therapeutic target for improving behaviour in PWS is being trialed.

In 2016, Dr Lauren Rice and colleagues at the University of Sydney discovered a correlation between reduced GABA levels and the level of behaviour disturbance experienced by an individual with PWS (emotional problems, temper outbursts and compulsive behaviours.) In a project funded this year by FPWR, they now plan to see if they can restore the balance of the GABA system using a GABA-modulating drug.

[Read more about this study and other treatments that can affect GABA levels here >](#)

Growth Hormone Therapy for Adults

Thank you to all the families who have been sending us observations regarding the effect on your child when GH treatment was ceased or restarted (as a child or adult.) 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 finding an adult endocrinologist and the cost of self-funding treatment because this is useful 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 families seem to be paying between \$62 - \$83 per month for a maintenance dose of 0.2mg.

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

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

New Action Plan for Learning Support

The [Learning Support Action Plan](#) 2019-2025 was launched on 26 July. Additional funding of \$29.6 million over four years was also announced to respond to population increase and growth of demand for learning support. The Action Plan sets out six priority areas which include Learning Support Coordinators in schools, strengthening early intervention and implementing a flexible set of services and supports for neurodiverse learners. This action plan builds on the new approach to providing learning support that is gradually being implemented across New Zealand following consultation.

Changes to Funded Family Care

The government announced long-awaited changes to the [paid family care policy](#) in July. The changes, which are a step in the right direction, include parents of disabled persons and an increase in wages paid. There is still some disappointment with the assessment process, the cap on 40 hours and lack of flexibility - campaigners believe there is more improvement required. The changes will come into effect in 2020 once legislation has gone through a Select Committee process.

PWS Training for Service Providers

For the remainder of the year, we have a couple of bookings for PWS training in Christchurch and Auckland. If you are based in those areas, we may be able to combine training needs and dates - please get in touch if interested. We are also planning our training schedule for other areas, plus looking ahead to next year. Please contact us to discuss your training needs. 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

Transition Expo Auckland - Tuesday 3rd September

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

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

Regional Notices / Events

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 (*Note: From Sept 4th there will be a charge of \$20 per family*)

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. (Note: Sib Camp Auckland 25th - 27th October @ Sir Peter Blake Marine.)