



February Newsletter

This is our first 2019 newsletter and we would like to wish you all a Happy New Year! As mentioned in our last newsletter, we are currently experiencing some staff changes as our CEO, Sarah McLarin, will be leaving at the end of March. We are looking for someone to join our team and fill this position - if this might be you, we would love to hear from you. Please contact jo.davies@pws.org.nz for further details and to ask any questions.

PWSA Events

We have a number of regional and national events coming up. These include regional family days for Wellington and Christchurch, a Tweens and Teens Weekend in May and a Young Families weekend in November. You may have already received details about these via email, but if not, the details are still being finalised and you will hear from us soon.

All these events are listed on our website [events page](#). Please check this page every now and then to read about PWSA events and other events of interest.



We would love to hold a regional family day for Auckland in the near future - please get in touch if you are able to help with this. It doesn't involve too much except being there on the day to meet everyone. We're also still looking for a regional family support coordinator for Auckland. Please ask for further details if you may be interested in this role.



Rare Disease Day - Feb 28th

We would like to support NZORD (New Zealand Organisation for Rare Disorders) with their Rare Disease Day campaign. If you would like posters to distribute in your community, please email comms@nzord.org.nz. The posters feature Sarah, Evie and Preston whose stories can be found on the [NZ Rare Disease Day website](#). Read more about what is happening for rare disease day both within NZ and in the PWS community, plus how you can show support on our Rare Disease Day [page](#).

Can you help with a media article?

NZORD are also actively campaigning for a review of Pharmac's processes, in particular, their response to applications for medicines by rare disease groups, which are frequently declined or experience long delays for approval. NZORD have asked if any families would like to share their story with a Newshub journalist? The interview focus would be the GH funding dilemma facing PWS patients as they become adults. It would only involve a telephone interview and there may also be questions about the joys and challenges of raising a child with a rare disorder. They would also speak to the PWSA about the difficulties and delays we have experienced with our applications to Pharmac. Please contact jo.davies@pws.org.nz if you can help.

NZ Clinical Trials Update

Liraglutide

GLP-1 is a gut derived hormone which reduces food intake and causes weight loss due to slowed gastric emptying and through direct central effects. Liraglutide is a GLP-1 agonist being trialed in PWS patients, with a study location in Auckland. This study is still recruiting and funding exists for patients and their family to travel for study visits during the trial. We asked Prof Paul Hofman for an update: *"The study run by Novo Nordisk is looking at the potential weight loss benefit of using the GLP-1 agonist liraglutide. It has been shown to cause impressive weight loss in adults (~10-15kg) and there is some early data suggesting substantial weight loss can occur in children and adolescents with PWS. The current study is a phase 3 trial where patients are randomised to either placebo or liraglutide and followed over the next 6-12 months. The study has been divided into 12-18 years which has just finished and we had 2 children with PWS involved and 6 to 12 years. This is mid way and we have 3 children enrolled to date. We are hoping to get 4 children by the time the enrolment period ends in July 2019. However if any family is interested they should call me for more details. The children have to be overweight (BMI>95th percentile) and otherwise well."* DDI +64 9 923 6453 Ext 86453

Mindfulness-Based Intervention for Temper Outbursts

Researchers at the University of Sydney are evaluating mindfulness-based intervention for managing temper outbursts and the impact on anxiety. Conducted remotely via phone, email and video-conference, this study is open to families within and outside of Australia. They are recruiting individuals with and without PWS, 13 to 30 years, who have a mild intellectual disability or typical IQ. Primary caregivers will be trained to use and teach the intervention. A teacher or support worker will help monitor behaviours. Click here to [read more](#) and contact [Dr Lauren Rice](#) if you are interested in participating.

You can keep up to date and read more about NZ clinical trial opportunities on our [research news page](#). If you are keen to read about what is currently happening in clinical trials worldwide, this [blog post](#) provides a very good summary.

[Read More: Overview of Clinical Trials for PWS](#)

New admissions criteria for residential special schools

Some children with PWS have benefited from a period of time at a residential special school, but obtaining a place at Salisbury or Halswell Schools has proven difficult at times. The MOE have introduced a new '[direct access pathway](#)' for residential special schools. You no longer have to be in the Intensive Wrap Around Service (IWS) and can apply directly. An RTLB teacher or special education teacher from MOE have to complete the application for you.

Education Survey - Tomorrow's Schools report

Our Schooling Futures, Stronger Together | Whiria Ngā Kura Tūātitini, the report of the Independent Taskforce on Tomorrow's Schools, was released on 7 December. You can [read the report and complete the online survey](#) to have your say or endorse its recommendations. Survey closes March 31st. Written submissions or any queries can also be emailed to: tomorrows.schools@education.govt.nz.

Taskforce-led [regional hui](#) on the report will take place in February/March 2019.

IPWSO Conference in Cuba

IPWSO invites you to save the date: 13-17 November

Conference programme:

- Scientific conference: 14 to 15 November
- Professional providers and caregivers conference: 14 to 15 November
- Parents and families: 16 to 17 November
- Activities for people with PWS: 16 to 17 Nov
- IPWSO General Assembly: 17 November



10th International Prader-Willi Syndrome
Organisation Conference
13 – 17 November 2019, Havana, Cuba

Key social events:

- Welcome reception: evening of 13 November
- Cuban dancing show: evening of 14 November
- Gala dinner: evening of 15 November
- President's event: evening of 16 November



Read more at the conference website and [register your interest](#).

Dates for your Diary

Drinks and Nibbles Evenings - coming soon!

PWSA(NZ) AGM - Saturday 23rd March

Tweens and Teens Weekend, Wellington - 17th-19th May

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

Regional Events

Show Your Ability Expo - Nationwide

26th February - 5th March

A free disability equipment expo roadshow making its way around NZ, starting Feb 26th in Auckland. A range of exhibitors will have information and resources to view, i.e. for housing modifications and supporting physical, OT and behavioural needs.

AUCKLAND – 26th February, ASB Showgrounds

HAMILTON – 27th February, Claudelands Event Centre

PALMERSTON NORTH – 1st March, Central Energy Trust Arena
CHRISTCHURCH – 4th March, Pioneer Recreation and Sport Centre
DUNEDIN – 5th March, Edgar Stadium

Click on the [event website](#) and location to find times and maps for the dates above. For further detail about exhibitors in your area, go to [this web page](#) and download the relevant floor plan.

Keeping Safe, Feeling Safe - New Plymouth

Weds 27th February - March 13th, 9.30-12.30

People First New Zealand and Safeguarding Vulnerable Adults Taranaki are holding a series of workshops about feeling safe and what to do if you are bullied or abused. [More info >](#)

Next Steps Transition Expo - Christchurch

Monday 15th April, 11am - 5pm

A transition expo which features stalls, information seminars, performances and enterprises from the support sector. Here is a link to the [Next Steps booklet](#) from 2018 which contains information on last year's presenters and stall holders. [More info >](#)

Transition Seminars - Canterbury

Sunday 14th - Monday 15th April

CHRISTCHURCH - Monday 15 April 2019, 11.30am, Haeata Community Campus, 240 Breezes Road, Wainoni (in conjunction with the Next Steps Expo)

RANGIORA - Sunday 14 April 2019, 3pm, Rakahuri Innovative Learning Environment, Rangiora High School. Afternoon tea provided and opportunity to connect with other young people, families and caregivers.

RSVP Kay Pearce: kay.chris.cam@xtra.co.nz or 027 448 0112 by Mon 8 April. [View flier >](#)

Care Matters Workshops

Parent to Parent Courses and Workshops

Disability Connect Workshops (Auckland) - new dates listed for 2019 (IF, Transition, Living Options etc.)

Parent to Parent branches for local support group meetings

Sibling Support Programmes - SibShops and SibCamps - these are advertised on the both the Parent to Parent and Care Matters calendars.