



February Newsletter

Happy New Year! We hope you have all been enjoying the Summer and that everyone has settled smoothly into 2021. We understand that the sudden 3 day lockdown could have been the cause of additional stress for our members in Auckland, so let's hope that we have seen the last of these abrupt events. Within the Covid-19 vaccination roll-out programme, we are pleased that the Government have considered a priority those with underlying health conditions and disabilities, residential care staff and carers of disabled persons whose welfare may be at risk if the carer falls ill. These vaccinations will be offered in [phase 3](#) before the general public roll-out later this year.

Regional Summer Events

We hope to announce dates and venues for regional family days very soon - details just being finalised. These will be days for both families and adults with PWS who are able to attend with a Support Worker. If you are keen to help coordinate an event in your area, please [get in touch](#).



We can advertise the event for you, manage RSVPs and provide some funding toward it - all you need to do is suggest a venue, date and be a point of contact on the day. Your event could be a bring a plate BBQ or picnic; meeting at a hired venue such as a community hall or local kindy; or meeting at an animal park or activity venue etc.

Fair for Rare NZ Campaign

We hope you will be able to help in giving this campaign a final push before the petition closes on March 17th. Rare Disorders NZ have worked really hard to bring public attention to the issue of a lack of government or health system policy for rare disorders. On Monday they have a meeting with Health Minister Andrew Little and on March 24th we will be attending alongside other rare disorder groups when they present the petition for a National Rare Disorders Framework at Parliament.



There has been lots of good publicity so far - you may have seen an article in last week's [Listener](#) that featured an interview with our CEO, Charlotte Roos. This week saw the broadcast of an excellent podcast on RNZ's The Detail in which two stories are shared illustrating why a framework is needed. One story is that of Sue Haldane who launched the petition to Parliament. Sue's daughter, Lizzie, has 22q Deletion Syndrome and their struggles will resonate with many parents of children with PWS, particularly if your child falls into the 'grey' area that exists today where some children do not qualify for learning support funding, transition funding and so on. These stories are very much worth sharing - [click here to listen](#).

What can you do?

1. If you haven't already, please sign and share one of the petitions, either on [Action Station](#) or the [parliamentary petition](#).
2. Share key messages across your social networks. You may wish to use our posts and slides on Facebook, change your cover pic or profile pic frame etc. #FairforRareNZ
3. Use Rare Disease Day on Feb 28th as a platform for sharing stories and key messages.
4. Check out the RDNZ [campaign resources](#).

Rare Disease Day - Donation Matching

If you or somebody you know were planning to donate to PWS research, the Foundation for Prader-Willi Research have a donation matching offer until Feb 28th (USA time) to celebrate Rare Disease Day. Visit their website to find out [how to donate](#).



Vagabond Family Blog

Paul, Emma, Lola and Isla (aka The Vagabond Family) are still travelling around New Zealand in their bus raising PWS Awareness and they would love to hear from you if you have any questions or if you would be interested in meeting up with them 'en route'. You can catch up on their travels by reading their [website blog](#) or by following them on Instagram. You can also [get in touch](#) with them via their website.

Medicines Update

Growth Hormone for Adults

A published [letter](#) to the Orphanet Journal of Rare Diseases by IPWSO argues that Growth Hormone should by now be universally available to both children and adults with PWS based only on a diagnosis of PWS. We hope that this paper will be useful when we submit again to PHARMAC asking for access

to be widened further to include funding for adults. There are few new studies being published regarding the use of GH in adults with PWS as it has already been widely proven to be beneficial and there are also the ethics to consider of terminating a treatment which is known to be successful in a young adult control group. As we have little new data not previously submitted to PHARMAC, it is really important that we keep gathering anecdotal data from families.

If you are one of several families now self-funding GHT for your son or daughter beyond end of growth, please keep us up to date with details such as dose required and any changes noted when the dose was changed or treatment was stopped / started. Likewise, if your son or daughter stopped treatment at end of growth and is no longer receiving GHT, please keep us posted on any changes or effects observed.

Semaglutide for Obesity

We have recently been asked about whether there are any plans to test semaglutide in patients with PWS. Semaglutide is a new diabetes medication which has been widely reported internationally to be a promising treatment for obesity, bringing about substantial weight loss by controlling appetite.

As Professor Paul Hofman at the University of Auckland has been trialing liraglutide, another drug in the same GLP-1 inhibitor group, we asked him for any further information about semaglutide's potential use in PWS. He informed us that there are no planned studies in PWS at present, but an oral form of semaglutide will be trialed in adolescents with type 2 diabetes later this year, with Auckland being one of the international sites. If this is successful in obese adolescents, there may well be a further trial in PWS, but this will all take time, possibly a few years. However, he is optimistic that this group of drugs does seem to have some effect on hyperphagia and weight gain in PWS.

In the meantime, we look forward to hearing the results of the liraglutide studies which are in the process of being published.

Possible termination of Andriol supply (oral testosterone)

We have heard that it is possible that PHARMAC may not be renewing their supply of Andriol, oral daily testosterone. This may be due in part to Covid related supply issues. If oral testosterone becomes unavailable in New Zealand, this only leaves the options of testosterone patches or monthly intramuscular injections and both of these options may be unsuitable for some individuals with PWS due to potential skin irritation or concerns regarding behaviour or mental health. An alternative is a gel form of testosterone which is not currently available here. Please [contact us](#) if you would like to have input to any feedback we provide to PHARMAC on this matter.

Caralluma Fimbriata Trial Opportunity

A reminder to [email us](#) if you wish to register interest in a possible, future CFE trial that can be extended to include NZ participants if there is significant interest. Thank you to those who have got in touch already. Some families in NZ participated in Joanne Griggs' [2015 study](#) and Joanne has recently provided an [update](#) on her CFE research and reports on the continued success of CFE supplementation for her daughter, Mia.



"We have determined CFE to significantly improve appetite behaviours in children and adolescents after 4-weeks treatment, compared to placebo, recorded by parent/carers. The highest response was at the recommended adult dose (1000mg/d CFE) in average weight participants."

Dates for your Diary

Virtual Social Evening for Parents of 6-12 year olds - Sun 28th February, 7.30pm

Zoom Chat for Tweens and Teens - Saturday 13th March, 2pm

Tweens and Teens Weekend - April / May date TBC, Wellington

Young Families Weekend - September / Oct date TBC, Wellington

NB. We are revisiting our Zoom Chat time slots, in particular the Zoom Chat for adults with PWS as Cindy is not currently available on Saturday afternoons to facilitate.

Notices / Events

Education, Disability and Your Child

March 8th via ZOOM, 10am-12pm or 7pm-9pm

by Parent to Parent

Free workshop. Learn how to get the best outcomes for your child with an Individualised Education Plan (IEP). [Register here >](#)

Planning for Adulthood: The Legal Framework

March 11th and May 13th, ZOOM only

April 14th, June 2nd and 23rd - Auckland venues

by Disability Connect

Formerly known as Trust and Welfare Guardianship seminar. RSVP essential. For further details and how to book, [click here >](#)

Transition Workshops: Life after school: what's next?

April and May, Napier and Nelson

by Imagine Better and NZDSN

Who Should Attend? 13 – 21 year old college students and their family / whānau, educators, Ministry of Education staff, service providers involved in 'transition', employment and day support, other key stakeholders.

Free for disabled students and their whānau. [Further information and registration >](#)

Employment Opportunities

Disability Connect have provided some useful information and links for those looking for opportunities, from fruit picking to employment agencies. [Click here >](#)

Many regional events and workshops are being presented online at the moment. 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.