



November Newsletter



The 'Vagabond Family' on the move for PWS!

Paul and Emma Doidge live in Northland, but will hit the road next year with their children, Lola and Isla, to raise PWS awareness and funds for PWS research. They will be travelling the length and breadth of New Zealand by bus, hoping to meet other families affected by PWS on the way and to share their journey with the world via their blog. You can read more about the inspirational Doidge family, their project plans and their previous adventures on their website: vagabondfamily.nz. Plus, if you would like to catch up with them on their travels around the country, you can message them on their [contact page](#). Paul and Emma would also like your help to decorate their bus by covering the sides in pictures of stick people families affected by PWS, bringing us on board with them! They will be asking families around the world to send them stick people pictures, but due to limited space, they want to ask the families affected within New Zealand first. So, kids or adults, if you would like to be involved, just have some fun drawing a little stick people portrait representing your family, take a photo with your phone and email it to: jo.davies@pws.org.nz. Please make pictures bold and black so as to be nice and clear!

PWSA News



Young Families Weekend 2019

Earlier this month we held a Young Families Weekend at the Top 10 Holiday Park in Christchurch. It was lovely to meet new people and we all enjoyed meeting the youngest member of the group, five month old Tommy, especially Sianna! Amongst others, a budding new friendship was formed between Sianna and Dekken who were inseparable for some time! These young families events are an informal and relaxing way of meeting new people and we were very lucky to enjoy some lovely weather at the same time! Click here to [view more pictures](#) from the weekend.



Family Camp 2020 - Register Now!

February 28th - March 1st, Taupo

MiCamp Taupo is a lovely, family friendly camp with accommodation in lodges with separate rooms. You should have received an email containing details about our summer camp there next year. Full details and updates can also be found on our website [events page](#). Please register by December 6th using our [online form](#). Please join us - all are welcome!

New Regional Coordinator for Auckland

We are very pleased to welcome Jo Te-Kapaiwaho who has volunteered for the role of Regional Coordinator for the Auckland region. Jo will help to coordinate social events for Auckland and will be a point of contact for families. Jo lives on the North Shore and is mum to 8 year old Miro who has PWS. Contact details for Jo and all our regional coordinators can be found under 'About Us' on the '[Your Association](#)' website page.

Training and Support Opportunity for Christchurch

We recently sent an email to families and service providers in the Canterbury region offering the availability of a PWS training day during the first week of December. We are offering this because we are aware that we haven't held training in the region for a little while, so we would like to remind you of this opportunity. If we were to hold a training day in Canterbury in December, Cindy would also be keen to visit some of our adults with PWS around Christchurch and perhaps organise a get-together for them. Cindy would also be available for any other family

support. Please [get in touch](#) if keen - this opportunity is likely to be postponed until March next year if we don't receive interest. Information about training can be found on our [training courses](#) page.

Congratulations Shannan Crow! \$1000 for FPWR!

Well done to Shannan Crow who won the People's Choice Award in the 2019 NIWA Staff Photo Competition for his photo '[The Centre of the Milky Way aligned with the Centre of Castle Hill](#)'. Shannan is father to 2 year old Elsie who has PWS and his winning entry won \$1000 for his charity of choice, The Foundation for Prader-Willi Research.

New Disability Action Plan 2019 - 2023

The Disability Action Plan 2019–2023 was launched on November 14th and presents priority work programmes and actions as part of the government's New Zealand Disability Strategy 2016–2026. The Disability Strategy is how the government will take steps towards meeting their commitment to the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD). To find out what we should expect in the years ahead, click here to view the new [Disability Action Plan](#). Click here to view the [TVNZ story link](#) with video.

International PWS Conferences

The 10th IPWSO Conference is currently taking place in Cuba. We look forward to hearing more about this from some of our families attending. You can view the conference programme here: www.ipwsoconference.org



The annual FPWR conference has also recently taken place in New Orleans - click here to view a [video playlist](#) of the conference presentations. Of particular interest to families and support workers will be the presentation on [Current Standards of Care for People with PWS Children and Adults](#) (this link provides useful timestamps so you can jump to portions of interest if you're short of time.) In another presentation, Jessica Duis also describes [Standards of Care specifically for ages 0-2](#). Families may also find the [Sensory Solutions](#) video useful (also with timestamps) which explains interventions and strategies that can be used at home.



Rare Disorders New Zealand Campaign

Rare Disorders New Zealand is part of Patient Voice Aotearoa, who are advocating for a reform of PHARMAC and doubling of the medicines' budget. There are several petitions for rare disease medicine access which are part of the collective call for improved access to innovative medicines. Parents of children with PWS will know of the long battle we have had with PHARMAC to widen access to growth hormone therapy and we can only imagine that we will face similar challenges with the funding of any new medicines on the horizon, such as carbetocin / oxytocin. Click the button below to read and sign the PVA petition.

The CEO of Rare Disorders NZ recently spoke on [TVNZ's Breakfast](#) about the challenges of accessing medicines in New Zealand. RDNZ have issued a call to action and are working with rare disorder groups such as ourselves in developing [7 strategic priorities](#) which they will ask to be addressed through the development of a National Rare Disorder Framework. There is a current lack of rare disease policy in New Zealand so it is hoped that when the final priorities document is launched at Parliament on Rare Disease Day next year, it will instigate broad policy change. The priorities include equitable access to medicines, a national rare disorders registry and improved government commitment to rare disease research.

[PETITION: Reform Pharmac and Double the Pharmac Budget](#)

New Social Enterprise

We would like to share a fantastic new social enterprise, [Will&Able](#), which is on a mission to create more jobs for people with intellectual disabilities. They provide high quality, eco-friendly cleaning products using 100% recycled NZ milk bottles. Follow their success on their [Facebook](#) page and click here to [order products](#).



Clinical Trial for males aged 12-17yrs with an ASD Diagnosis

The purpose of this study is to investigate two potential products that act through changing gastrointestinal (GI) function. Click to find more information on the [Australian New Zealand Clinical Trials Registry](#). The study site in NZ is a clinic at Grafton, Auckland. Eligible participants will have 6/7 visits to the clinic over the course of 4 months and may receive compensation for travel. You can find out more from: research@autismnz.org.nz

Dates for your Diary

Family Camp Taupo - Friday 28th February - Sunday 1st March
Rare Disease Day 2020 - Saturday 29th February

Regional Notices / Events

Autism Research Public Seminar, Auckland

Monday 25th November, 6.30 - 8pm, Faculty of Medical and Health Sciences, University of Auckland

Minds for Minds, together with the Centre for Brain Research and Autism New Zealand, presents: Autism Research Public Seminar - an update on autism research with a focus on answering your questions. Chaired by Dr Rosamund Hill (neurologist) with additional panel members Jen Birch (author and advocate) and Dane Dougan (Chief Executive - Autism NZ) Click here for [further details and to register](#).

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](#).

[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 (*From Sept 4th, a charge of \$20 per family applies*)

[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.