



## December Newsletter



This is our last newsletter for 2018 and we wish you all a safe and Merry Christmas with best wishes for the New Year.

### Staff Changes

In 2019 we will be experiencing some staff changes as Sarah McLarin, our CEO, will be leaving at the end of January. Sarah has been our CEO for 3 years and will be missed. We are currently looking to fill this position - if you are interested and want to find out more, please contact our board Chairperson, Karen

O'Reilly: [oreillynz@outlook.com](mailto:oreillynz@outlook.com)

## PWSA Regional Events

As you will have noticed, the regional family events that were proposed for December were not confirmed and unfortunately had to be postponed. We hope to be able to hold these days for families and adults with PWS in February 2019.

**POSTPONED**

We are also hoping to hold some drinks and nibbles evenings for parents during March. (For those invited to the Young Families Weekend originally planned for March - this will now be taking place in November.)



## PWSA Resources

If you ordered teacher packs for the new school year, hopefully they have all been safely received. We will be able to send out more copies in January for those who still require them. Please [order here](#) via our website.

We still have some of the new Nutrition Guidelines books available as per our previous 'New Resources' email. Information about these books can be found by clicking on their titles in [our library](#), but if you think your own copy to keep would be useful, please send a request to: [jo.davies@pws.org.nz](mailto:jo.davies@pws.org.nz)

## Diet Information

In this 5 minute video clip, Melanie Silverman, expert dietitian for PWS, provides a useful [overview of the low carb diets](#) becoming more frequently used for children with PWS today (MAD, Keto and Paleo).



In another short clip, Melanie explains how she used a [Mediterranean Diet](#) to help Latham Centers modify their menus to include more fat and fibre with positive results.

If you would like to watch the full presentation, click here to send a [request to FPWR](#). You can also listen to Melanie's presentations at the recent Asia-Pacific PWS Conference in Brisbane via our [You Tube](#) channel.

[Read more about diets for PWS](#)

## Useful Sex Education Resources

The PWSA(UK) has produced some great resources for teaching people with PWS about puberty, growing older, relationships and staying safe. These are in the form of [3D animations](#) for young people and adults with PWS aged 11+ and come with downloadable accompanying notes. Read further about [Sexual Development](#) in PWS.

## 'I Choose' Update

Those who use Carer Support respite will be aware that 'I Choose' was due to be implemented Dec 1st 2018, but has been delayed. The Ministry of Health intend to announce a new start date in the New Year. In the meantime, click here for updated

information about [I Choose](#) and you can continue to use Carer Support forms. You do not need to do anything and will be told more at the time of your review once implementation is underway.

## Other News...

Did you hear about Disability Pride Week? This is an event which celebrates our common humanity and is gathering momentum. It took place Nov 26th - Dec 3rd in 2018. Read more at [www.disabilityprideaotearoa.nz](http://www.disabilityprideaotearoa.nz).

We think you might find the following Disability Support Service publications by the Ministry of Health of interest: [DSS Quarterly Newsletter](#) (Nov) and [DSS Special Edition](#) (Dec).

### Dates for your Diary

Regional Family Days - February  
Drinks and Nibbles Evenings - March  
PWSA(NZ) AGM - 2nd to last weekend of March  
Tweens and Teens Weekend, Wellington - May  
Young Families Weekend - November

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## Regional Events

### **Phab's Holiday Hangouts - Takapuna, Auck.**

Days for over 16s with Playstation 3, TV, video camera, pool table, table tennis, air hockey, foosball table, liberty swing plus other games and outdoor equipment. Cost = one day carer support day. [More details >](#)

### **Give it a Go Day - Mt Smart Stadium, Auckland**

Sunday 10th February, 10am - 2pm

A free family event for kids of all ages with disabilities. [Register here](#) for your free tickets.

### **Disability Action Plan Workshops - National**

11th - 21st February: Lower Hutt, Nelson, Auckland, Waitakere, Napier - various times

The Office for Disability Issues and the Disabled Peoples' Organisations Coalition are holding workshops to gather ideas about what should be in the new Disability Action Plan 2019–2022. [More info and RSVP >](#)

### **NZORD Education Session - Wellington**

Tuesday 26th February, 10am - 12.45pm

The chance to meet, talk and share with others living with rare disorders. Two speakers and a workshop dedicated to addressing some of the challenges faced. Free. [Register here](#).

## **Disability Awareness Day - Pakuranga, Auck.**

Saturday 13th April, 10am - 3pm

Provides disabled people, whanau and organisations an opportunity to meet agencies who provide support for people with disabilities in any form across the Auckland Region. It is also an opportunity to showcase a variety of performances by groups of people with disabilities. Contact Disability Connect by Feb 28th if you wish to exhibit and book a stall. [More info >](#)

Care Matters Workshops

Parent to Parent Courses and Workshops

Disability Connect Workshops (Auckland)

Parent to Parent branches for local support group meetings

Sibling Support Programmes