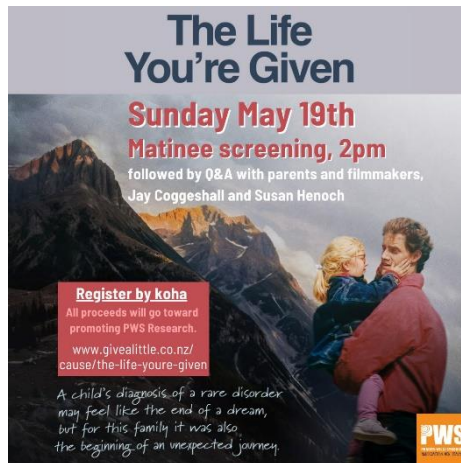


News Bulletin - May 2024



Links to join our special virtual screening of THE LIFE YOU'RE GIVEN will be sent out on Saturday, which means there is a final opportunity [to register >](#)

We are delighted that Jan and Susan, parents and filmmakers, will be joining us afterwards from the USA for a live Q&A session. [Read more / watch the trailer here >](#)

Awareness Month Updates

We are now halfway through PWS Awareness Month! Thank you to everyone who has been helping us spread awareness by sharing information about PWS. Please keep on sharing!

Orders already received for [ribbons, wristbands and posters](#) will be sent out next week. Please check your email replies regarding any Tshirt orders. If you would still like to order resources, it's not too late to get your orders in!

<p>PRADER-WILLI SYNDROME</p> <p>PWS occurs due to missing or inactive genes on chromosome 15.</p> <p>This affects the hypothalamus, an organ in the brain which produces hormones that control growth, muscle development, metabolism, hunger, mood, the expression of emotions, the sleep/wake cycle, temperature, and the feeling of pain.</p>	<p>PWS PRADER-WILLI SYNDROME ADVOCACY • EDUCATION • SUPPORT</p> <p>PWS is a rare & complex disorder.</p> <p>Wide ranging symptoms form a spectrum which impacts physical, cognitive, behavioural, hormonal, and sensory function differently for each person.</p>
<p>FRIDAY 31ST MAY 2024</p> <p>PWS Awareness day</p> <p>RAISE AWARENESS AND SHOW SUPPORT FOR PEOPLE LIVING WITH PWS AND THEIR FAMILIES BY WEARING ORANGE, SHARING YOUR PWS! </p> <p>www.facebook.com/PraderWilliSyndromeAssociationNZ</p>	
<p>DONATIONS / PROCEEDS TO RESEARCH:</p> <p>www.givealittle.co.nz/org/pwsresearch</p> <p>www.givealittle.co.nz/org/pwsasupport</p>	<p>Awareness leads to acceptance and understanding</p> <p>For more information www.pws.org.nz 0800 4 PWS HELP</p>

Thank you also to everyone who has sent a picture for our community spotlight on [social media](#). If you haven't seen your picture yet, it will be posted soon! It would be lovely to have a few more pictures to share - please keep [sending them](#) with a little bit of information, i.e. something that makes you proud, a milestone, achievement, a goal being worked towards, or a challenge overcome.



Awareness Tshirts and Hoodies

We are also pleased to announce that our new [merchandise store](#) is now up and running, and we currently have Tshirts and Hoodies in various styles available. The idea behind this is that you are now able to shop when you want and get the sizes you want, with all purchases managed through Digitees. Please bear in mind that the creation of this store is a work in progress and we have limited designs uploaded at this stage - more coming soon! As this is very new, we are also waiting for the results of our first test run to check the print quality. This will be available later next week. In the meantime, please feel free to order if you wish, but be aware that although the print quality should technically be fine, it has not been tested yet.

Website link: www.pwsanz.digitees.co.nz



Petition for DCCR - potential hyperphagia treatment

As mentioned in our previous newsletter, a petition to the FDA in the USA is advocating for the approval of a new drug application for DCCR, which will be submitted mid-2024. The petition closes on **May 23rd** and the international PWS community is being urged to share what the approval of DCCR would mean to them. [Participate here >](#)

DCCR is a potential treatment for hyperphagia in a phase 3 clinical development programme by Soleno Therapeutics. It is thought to affect leptin pathways by opening KATP channels in the brain, pancreas and fat tissue. (Leptin usually helps to regulate energy balance by inhibiting hunger - a pathway

that is believed to be disrupted in PWS.) DCCR has the potential to regulate appetite, reduce body fat, and improve insulin resistance.

Some good news for the speed in which this new drug application will be processed is the granting of Breakthrough Therapy Designation to DCCR, which the FDA granted based on assessment of preliminary data. It is now possible that FDA approval for DCCR could be achieved by the end of the year, the first step in widening approval internationally.



OUR MESSAGE TO THE FDA:

**FILE DCCR'S NEW
DRUG APPLICATION!**

SIGN ON NOW

DEADLINE: MAY 23, 2024

PETITION

**PRADER-WILLI SYNDROME
ADVOCACY COALITION**

The banner features a teal and dark blue color scheme with geometric patterns. It includes a 'PETITION' card with a signature and a globe icon. The text is bold and clear, emphasizing the deadline and the call to action.

Prader-Willi Syndrome Association New Zealand

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