

## April 2024 Newsletter

### May is PWS Awareness Month!

If you would like ribbons, wristbands and posters ready for 'going orange' on **Friday 31st May**, please order these from our [Awareness Resources](#) web page. We have very few T-shirts remaining of those advertised on our website, but we have some exciting new styles and designs which will be ready for you to order very soon!

'Save the Date' for our awareness month film fundraiser on **Sunday May 19th**. We are very pleased to be able to bring you a virtual screening of new film, *THE LIFE YOU'RE GIVEN*, followed by a live Q&A with parents and filmmakers, Jay Coggeshall and Susan Henoch. Filmed over 35 years, Jay and Susan offer an intimate and honest portrait of their journey as they navigate the challenges and unexpected joys of dealing with a little-understood and rare genetic disorder. Jay Coggeshall has directed and produced numerous documentary films. He initially started filming his daughter Sophie to create family memories, but when she received a diagnosis of Prader-Willi syndrome at 3 years old, Jay decided to make a film about PWS. This film is being screened as a fundraising event for PWS research. Registration will be by koha - details on how to register will be in a separate email that you should receive very soon. Everyone is welcome - parents, whānau, friends and support networks.

# The Life You're Given

**Save the date: Sunday May 19th**

**Matinee screening, 2pm**

followed by Q&A with parents and filmmakers,  
Jay Coggeshall and Susan Henoch

**Register by koha**

(details coming soon.)

All proceeds will go toward  
PWS Research.

**PWS** PRADER-WILLI SYNDROME  
ASSOCIATION NEW ZEALAND  
ADVOCACY • EDUCATION • SUPPORT

*A child's diagnosis of a rare disorder  
may feel like the end of a dream,  
but for this family it was also  
the beginning of an unexpected journey.*

Film running time  
is 85mins, Q&A will  
begin at approx.  
3.30pm.

We are also very  
happy to support  
any awareness or  
fundraising ideas  
you have for May.

If you have any  
questions about  
how we can help,  
please don't hesitate  
to [contact us](#).

As we do each year, we will be sharing information about PWS during May via social media, and we will also be repeating last year's Community Spotlight.

Please help us to shine a spotlight on people living with PWS by [sending us a photo](#) and sharing something that makes you proud, or an achievement / milestone, or a goal being worked towards. Or you might want to share a challenge that has been overcome. Just write a few short sentences, or we can help do this for you.



## Asia Pacific PWS Conference 2024



During May, registration will be opening for the [Asia Pacific PWS Conference](#) in Sydney, Aug 30th-31st, with early bird rates **closing May 31st** (345 AUD for 2 days.) Early bird rates only apply to in-person registration and not virtual registration.

Day 1 (Aug 30th) – Research Day, led by the Prader-Willi Research Foundation Australia (PWRFA), fostering collaboration and inspiring fresh insights.

Day 2 (Aug 31st) – Parent, Professional and Support Providers Day – genetics, neurotypical behaviours, health care, physiotherapy, nutrition, sleep, and more! There will also be a concurrent programme for professional support service providers.

The conference website, with further programme information and registration details, will be going live at the beginning of May. Details coming to your inbox very soon.

## Thank you, and Congratulations!

We would like to say a huge thank you to Craig James, who ran the Paris Marathon in April and has [raised \\$2222](#) for the PWSA(NZ)! Craig is a work colleague to young Charlie's dad, Cameron. Charlie's parents, Rebecca and Cameron, have been members of the PWSA since Charlie was just a few months old.

### For Charlie & families with PWS.

Fundraising for Prader-Willi Syndrome Association NZ

Nationwide



\$2,222 of \$2,000 goal

Given by 37 generous donors in around 5 months

Donate

Share

We would also like to say many congratulations to Greta and Ben in Auckland, who were married in March and very kindly asked for donations to the PWS Association. We received some very generous donations and would like to thank Greta and Ben's friends and family. Greta and Ben are parents to 3-year-old Neoma diagnosed with PWS.

## Advocacy Updates

### Medicines Applications

We submitted 4 applications to Pharmac in early March: another request for growth hormone to be funded for adolescents and adults beyond end of growth (currently approved but on the Options for Investment list), for [guanfacine](#) (a non-stimulant ADHD medication which has been trialled in PWS by [Dr Deepan Singh](#) for impulsive and aggressive behaviours or agitation), for [pitolisant](#) (a medication for excessive daytime sleepiness currently beginning [phase 3 trials](#) for PWS and with wider benefits, [1](#) and [2](#)), and [pharmacogenomic gene tests](#) for psychiatric medications, to guide precision healthcare, especially for [patients prone to adverse or atypical reactions](#) (as in [PWS](#)).

### Changes to Disability Support Funding

Since the sudden changes to the purchasing guidelines on March 18th for Individualised Funding, EIF, Choice in Community Living, EGL, Personal Budgets and Carer Support, we have listened to community concerns and attended two meetings with Whaikaha. Please keep letting us know if the changes are causing significant distress. In order to help us continue advocating on behalf of the PWS community, it would be useful to continue conversations on this issue - please keep us informed if the changes are negatively impacting you and let us know if another family meeting would be helpful.

### Review of Adult Decision Making Law

In March 2023, we submitted a [response](#) to the New Zealand Law Commission who are reviewing the law relating to adult decision-making capacity. We outlined some concerns specific to Prader-Willi syndrome. The [Second Issues Paper](#) is now published (available in different formats) and looks at the current law in more detail and suggests possible options for reform. Submissions on this paper are invited by [Friday 21st June](#) and this feedback will inform the recommendations made in the Final Report to the Minister of Justice in early 2025. We intend to carefully review this paper, but please take a look if you are interested, and we would be keen to hear any thoughts.

## Introducing Bjørn Christensen



We would like to introduce you to Bjørn who is a Regional Service Manager at Community Connections in Wellington. Bjørn has managed a service for an adult living with PWS for 4.5 years and will be heading to [IPWSO's International Caregivers Conference](#) in Berlin during May. We are very pleased to be supporting Bjørn to attend this 3 day conference, and Bjørn is also the recipient of an IPWSO Travel

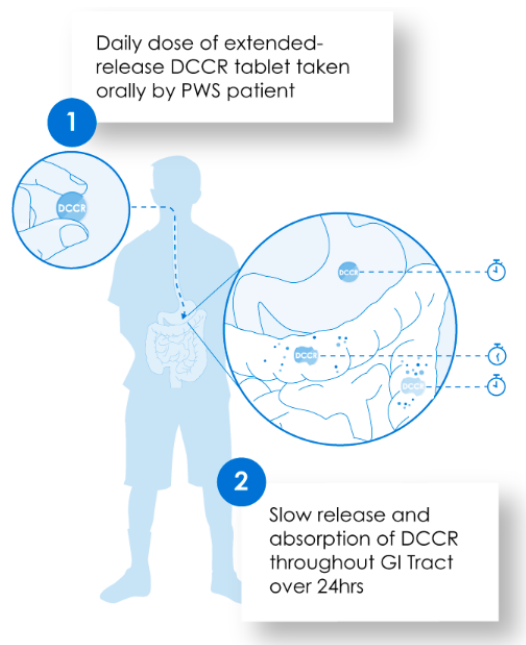
Scholarship, kindly sponsored by Friends of IPWSO (USA). The conference enables support providers worldwide to exchange practice-driven knowledge to enhance the care they provide and develop new strategies for support.

The conference will cover topics such as the future of PWS support, relationships, technology, balancing individual rights with the duty of care, diagnostic instruments in behaviour management, the role of therapies, autonomy, ageing, and more.

Bjørn believes there are many complexities and nuances involved in providing a successful service for someone living with Prader-Willi syndrome and he is always seeking ways to improve. He hopes that by attending this conference, he will be able to establish connections, learn new strategies and come away with a greater understanding of what other communities are doing around the world to provide safe, happy and exceptional support for people living with PWS.

After the conference, Bjørn will share his learning with his team and with the PWS Association. We look forward to hearing all about the conference and benefiting from his input into some of our future projects, including a Transition Event which is planned to take place in Auckland, October 18th-19th 2024.

## DCCR - Breakthrough Therapy Designation



DCCR, a potential treatment for hyperphagia, is still in a phase 3 clinical development programme, but Soleno Therapeutics are focused on submitting a New Drug Application (NDA) to the FDA (Food and Drug Administration USA) around mid-2024. Some great news for the speed in which this NDA 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 if approval for DCCR is obtained, this could be achieved by the end of the year! This would be the first step in widening approval internationally.

### WHAT IS BREAKTHROUGH THERAPY DESIGNATION?

"The FDA's Breakthrough Therapy Designation is intended to expedite the development and review of drugs in the U.S. that are intended to treat a serious condition, when preliminary clinical evidence indicates the drug may demonstrate substantial improvement over available therapy on a clinically significant endpoint(s). With Breakthrough Therapy Designation, FDA provides intensive guidance and organisational commitment involving senior managers in a proactive, collaborative, cross-disciplinary review, and may also allow for priority review and other actions to expedite review."

In further advocacy toward a successful application for the approval of DCCR by the FDA, the PWS Association in the USA are urging the PWS community to share what the approval of DCCR would mean for them, by completing the following [petition / survey](#). Please sign the petition **by 23rd May**.



## Residential Support Service Provision Research

A newly published [open access study](#) may be of interest to support service providers. Analysing data from 11 services in 6 countries: Denmark, Germany, Ireland, Switzerland, UK and USA, it concludes that full-time care services offer people living with PWS opportunities to thrive, especially if they are specialised around the particular needs that arise from PWS. It illustrates the potential of full-time professional care to transform the lives of people living with PWS, by elevating and maintaining their physical and behavioural well-being.

## Parent Reminder: Families living with PWS Study

Information regarding this study has already been emailed to families, so thank you if you have already taken part.

[The study](#) is examining the experiences and well-being of families living with Prader-Willi syndrome. Please consider taking part because participation from diverse countries around the world will help to provide a realistic picture of the challenges families face, and the results from this study will be useful when advocating for supports for people living with PWS and their families. It involves an [online questionnaire](#) that takes 20-25 minutes to complete. Please consider taking part before June 2024.

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## Notices / Events

### Dates for your Diary

**PWS Awareness Month - May 2024**

**The Life You're Given Film Screening - Sunday 19th May @ 2pm**

**PWS Awareness Day - Friday 31st May**

**PWSA(NZ) AGM - Sunday 9th June @ 2pm**

**APPWS Conference early bird registration closing - May 31st**

**Asia Pacific PWS Conference, Sydney - 30th - 31st August, 2024**

**PWSA(NZ) Transition Symposium - Fri 18th - Sat 19th October, Auckland**

**IPWSO Conference, Phoenix, USA - 24th - 28th June, 2025**

### **Disability Supports – Work and Income Support Seminar – Taikura Trust – 10<sup>th</sup> May**

A free presentation (for families) to learn more about disability supports available to you.

Date / Time: Friday 10<sup>th</sup> May, 9.30am – 12.30pm

Venue: Massey Community Trust, 8 Vadam Rd, Massey, West Auckland

[More information here >](#)

### **StarJam Online**

As StarJam continues to grow and there are sometimes waitlists, they have looked at ways of reaching out to more people and engaging new Jammers. Two new online workshops have begun this year:

Screen Superstars - 6 - 7.30pm Thursdays

Online Sensations - 4 - 5.30pm Thursdays

Click here to complete an [online expression of interest >](#)

[StarJam website >](#)

Many regional events and workshops are now being presented online. 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 (Thurs 25<sup>th</sup> July 6.30pm-9pm via Zoom), 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.

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#### **Contact Us:**

[www.pws.org.nz](http://www.pws.org.nz) | [enquiries@pws.org.nz](mailto:enquiries@pws.org.nz) | 0800 4 PWS Help

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