Discover Care Thrive

6TH ASIA PACIFIC PRADER-WILLI SYNDROME CONFERENCE

30TH - 31ST AUGUST 2024
SYDNEY, AUSTRALIA

SPONSORSHIP PROPOSAL

The 2024 Asia Pacific PWS conference will showcase the latest in PWS research and care for researchers, clinicians, families, and those working in health and support roles. Being held in Sydney, Australia on August 30 & 31, it is hosted collaboratively by Prader-Willi Research Foundation Australia, Prader-Willi Syndrome Australia, PWSA New Zealand, PWSA Malaysia and PWSA Thailand.

The conference features:

- Research Day (August 30), dedicated to fostering collaboration and new insights.
- Adults Living with PWS Programme (August 30), listening to the voices of lived experience.
- Family and Professional Day (August 31), designed to equip attendees with the latest in PWS care, support and management, and an opportunity to share experiences.
- Residential Support Providers Programme (August 31).

Leading international plenary speakers:

Dr Deepan Singh, Psychiatrist, clinical trial expert and author of Neurobehavioural Manifestations of Prader-Willi syndrome.

Prof Tony Holland, Psychiatrist, researcher, and President of the International Prader Willi Syndrome Organisation (IPWSO).

Plus, a host of local and international experts, such as Prof Laura de Graff (growth hormone), A/Prof David Godler (genomics and newborn screening), Dr Janet Franklin (healthy eating), A/Prof Honey Heusler (Centre of Expertise) and Dr Duangrurdee Wattanasirichaigoon (genetics and equity), and many more to be confirmed.

WHY SPONSOR THIS EVENT

People living with PWS urgently need improved medical care and treatment options, which are possible through research, education, and community building. People living with PWS also typically need multi-dimensional support throughout their lives, but show remarkable strength, resilience, and courage.

This three-yearly international conference brings together the whole PWS community to connect, learn and problem-solve to improve the lives of people living with PWS and their families.

The 2024 Asia Pacific PWS Conference relies on the generous support of organisations and businesses such as yours. Prader-Willi Research Foundation Australia, Prader-Willi Syndrome Australia and Prader-Willi Syndrome Association New Zealand are all registered charities with DGR status in Australia and donee status in New Zealand.

We invite your organisation to support this unique event and benefit from the opportunity to share your brand with an audience comprising delegates from across the Asia Pacific region, from India to Japan. The anticipated audience will include leading researchers, clinicians, allied health professionals, support agencies and organisations, educators, students, and families. In addition to the physical conference being held in Sydney, your support will also enable us to provide a virtual registration option to reach a wider audience of attendees who are unable to attend in-person.

This conference will be advertised across the Asia Pacific region and internationally via the websites, social media platforms and communication channels of each organising country. There is also a dedicated conference website currently being developed. The PWS Associations of Australia, New Zealand, Malaysia and Thailand are all members of the International PWS Organisation (IPWSO) which provides additional strength and connectivity to the international PWS community.

The Research Day brings together international and local researchers, students, and families. In addition to leading international research, we will showcase PWS research from the Asia Pacific region, which is making a significant contribution to the global progress towards finding treatments. We aim to:

- Identify and address emerging issues and debates.
- Strengthen research and practice.
- Explore potential collaborations & partnerships across boundaries of disciplines and sectors.

The Adults Living with PWS Programme offers opportunity to hear the voices of people living with PWS – what they can teach others and what they want to achieve in their own lives.

The Family, Professional, and Support Providers Day will deliver latest insights on the care and therapies critical to supporting someone living with PWS, whether in the family home or residential setting. Topics covered will include clinical support, treatments, nutrition, behaviour, sleep, mental health, and wellbeing, with a concurrent programme dedicated to residential support providers.

As a sponsor, you will play a vital role in supporting the dissemination of knowledge, promoting awareness, and fostering meaningful connections within the Asia Pacific Prader-Willi syndrome community as we work together towards establishing standards of care and expertise.

Join with us to make a lasting impact.

CHOOSE TO SPONSOR:

- **Both days to build your engagement with the Asia Pacific PWS community.**
- **The Research Day to align your brand with innovative, person-centric research that is making ground on the world stage.**
- **The Family, Professional and Support Providers Day and/or Adults Living with PWS days to demonstrate and build your position in delivering to their needs.**

SPONSORSHIP PACKAGES

Research Day, or Family, Professional and Support Providers Day, or both.

BENEFITS	PLATINUM	GOLD	SILVER	BRONZE
Sponsor-specific space on Conference, PWRFA & PWSA websites (Website & email details)	✓	✓	✓	✓
Sponsor banner / Logo on email correspondence to conference delegates[1]	✓	✓	✓	✓
Acknowledgement during conference	✓	✓	✓	✓
Logo on conference program and website	✓	✓	✓	✓
Brief introduction of your organisation in email correspondence to conference delegates (rotating between sponsors)	✓	✓	✓	
Sponsor space on holding slides / conference streams	✓	✓	✓	
Opportunity to display pop up banner at Event	✓	✓		
Opportunity to display promotional materials within designated space at event	✓	✓		
Sponsor mentions on social media & media	✓	✓		
Deliver a content presentation at the conference (format & duration varied by sponsor tier)[2]	✓			
Logo displayed on name tags	✓			
OPTIONAL ADD-ONS				
Sponsor Key Speaker – Dr Singh or Prof Holland	✓			
Sponsor a session or lunch	✓	✓		
Sponsor a table for the day	✓	✓		
Sponsor morning or afternoon Tea	✓	✓		
Host a breakfast	✓	✓		
Sponsor a student prize	✓	✓	✓	✓

1 Distribution of promotional materials to existing consented stakeholders: ~10,000 people
2 Sponsor speaking opportunity: short speaking slot (can be promotional) before a keynote speaker. Content must be approved by Conference Committee prior to event.

DISCOUNTS AVAILABLE TO FULL CONFERENCE SPONSORS AND TAILORED PACKAGES AVAILABLE.

Contact us to discuss sponsorship opportunities further.

PLENARY SPEAKERS

Dr. Deepan Singh is a board-certified child, adolescent, and adult psychiatrist, who currently serves as the Vice-Chair of Ambulatory Psychiatry Services at Maimonides Medical Centre in Brooklyn, NY. Over the past eight years, Dr. Singh has developed a strong interest and expertise in the management of Prader-Willi Syndrome. He has numerous peer-reviewed publications and presentations on the behavioural aspects of PWS. He remains active clinically, and in clinical research. He serves on the scientific review boards for Prader-Willi Syndrome Association (USA) and the Foundation for Prader-Willi Research. He is also part of the International Prader Willi Syndrome Organisation's Mental Health Network.

Dr. Singh's most recent work is his book "Neuro-behavioural Manifestations of Prader-Willi Syndrome: A Guide for Clinicians and Caregivers", which is an easy-to-read resource for all clinicians and caregivers caring and supporting persons with PWS.

Prof Tony Holland is the President of the International Prader-Willi Syndrome Organisation (IPWSO). Prof Holland trained in Medicine at University College and University College Hospital, London, qualifying in 1973.
After some years in General Medicine, he trained in Psychiatry at the Maudsley Hospital and Institute of Psychiatry in London. In 2002 he was awarded the Health Foundation Chair in Learning (Intellectual) Disability establishing the Cambridge Intellectual and Developmental Disabilities Research Group (www.CIDDRG.org.uk).

The conference will be held in person **with livestreaming and recording of sessions,** making the conference easily accessible for audiences in Australia, New Zealand, and across the Asia Pacific. As a result, we are expecting to attract a diverse range of speakers.

ABOUT US

Prader-Willi Syndrome (PWS) is a randomly occurring genetic condition affecting around 1 in 15,000 newborns. Due to some inactive genes on chromosome 15, people with PWS have complex medical needs and develop hyperphagia, the hallmark feature of dysregulated appetite with an overriding drive to eat. Other typical features are global developmental delay, challenging behaviours, and mental illness.

The 2024 Asia Pacific PWS Conference is a collaborative initiative being hosted by key bodies driving research and parent support of the PWS community in the Asia-Pacific, namely Prader-Willi Research Foundation Australia, Prader-Willi Syndrome Australia, Prader-Willi Syndrome Association New Zealand, PWSA Malaysia and PWSA Thailand.

Prader-Willi Research Foundation Australia

PWRFA exists to transform clinical outcomes and available treatments for people living with Prader-Willi Syndrome. We fund cutting-edge research to help people with Prader-Willi Syndrome live independent lives, free from the most debilitating symptoms.

PWRFA funding has accomplished the following achievements within the research and development space:

- 2018 – PWRFA Funded Professor Marnie Blewitt from WEHI to test and develop a potential mechanism for activating the Magel2 gene cluster.
  The Blewitt lab is now working on a global contender for a gene activation treatment for PWS, with 4 full-time and 3 part-time scientists. We continue to fund Prof Blewitt's research.
- 2020 – Establishment of a Chromosome 15 Biobank in collaboration with A/Prof David Godler at the MCRI.
- 2023 - PWRFA announced funding for Australia's first PWS dedicated Nurse Coordinator, as the first stage in the PWS Centre of Expertise. Working with the clinical team at Queensland Children's Hospital the nurse will provide PWS centric care coordination for newborns and children diagnosed with PWS.
- 2023 – Funding Professor Marnie Blewitt at WEHI (Walter and Eliza Hall Institute of Medical Research) to progress early work on an antisense oligonucleotide (ASO), which so far indicates some activation of the silenced maternal genes in the PWS region. This a potential treatment relevant to all people with PWS.

PWRFA is a registered health charity, ABN 21 605 291 816, with DGR status.

Prader-Willi Syndrome Australia

Prader-Willi Syndrome Australia Ltd (PWSA) is a family-focused organisation. We strive to improve quality of life for all people living with PWS. We're proud to be building an inclusive, respectful and collaborative organisation that places individuals living with PWS at the heart of all that we do.

Our vision is a world where every person living with PWS has equal access to high quality services and supports so they can live happy and productive lives. To overcome current inequities and to improve services for people with PWS and their families, PWSA has a great responsibility to reach families all across Australia. Efforts of PWSA include information and knowledge sharing and peer support. We harness modern technology to achieve its vision.

PWSA's mission is to simplify knowledge pathways by connecting, educating, advocating and transforming lives together. PWSA exists to empower those impacted by PWS. We work together to transform lives through collaboration, education and advocacy with individuals, professionals, mainstream services and members of the wider community.

PWSA looks forward to co-hosting this vital conference to benefit families, researchers, support workers and the PWS community, giving insights into many dimensions of supporting someone living with PWS.

Key achievements include:

- Established an Australia-wide peer group for adults living with PWS, who meet regularly to build leadership skills and increase opportunities; it's called OWLA (Our Way of Life Australia).
- Made videos featuring OWLA members who share knowledge from their lived experience.
- Made various submissions to Government and NDIS consultations highlighting the issues facing and needs of the PWS community.
- Delivered training sessions for providers that offer services to people living with PWS.

PWSA is a registered HPC charity, ABN 12 625 483 909, with DGR status.

Prader-Willi Syndrome Association New Zealand

The PWSA (NZ) was founded in 1989 and has served as an incorporated society since 1991, with charitable status since 2008. Our mission is to enhance the lives of New Zealanders living with Prader-Willi Syndrome and their families by providing advocacy, education, and support.

Key achievements include:

- Successfully advocating for funded growth hormone therapy for children and adults with PWS.
- Making submissions to Government ministries, Pharmac, medical societies, and in relevant consultations, to create awareness of issues faced and advocate for the needs of the community.
- Collaborating with professionals and other agencies to improve the care and supports available, for example, working with Rare Disorders NZ to support the establishment of a Rare Disorders Health Strategy and a Centre of Expertise within national health system reforms.
- Producing and regularly updating a wide range of free information resources which are sent to hospitals, families, schools, service providers, and to disability / health events and conferences.
- Regularly delivering PWS training workshops to schools and residential service providers.
- Hosting biennial national camps for people living with PWS of all ages to attend with their families or a support person.
- Hosting age specific weekends each year on a rotational basis: for young families, for tweens / teens living with PWS and parents, for adults living with PWS.
- Establishing an Adults Living with PWS (ALPWS) Leadership Group in 2018 who have met in-person at camps and adults' weekends and meet regularly via Zoom. The ALPWS group set goals for what they would like the group to achieve and have worked on self-advocacy, peer support, contributed to information resources, and have recently produced videos for PWS training.
  In 2023, they selected their first ALPWS representative to join the PWSA(NZ) Board.
- Providing all-hours, year-round support and advocacy as needed to families and individuals who can contact us in several ways online and via our helpline.

PWSA(NZ) is a registered charity, CC460009, with donee status.

CONTACT

For further information please contact one of the below designated personnel:
nicole@praderwilli.org.au **Operations Coordinator, PWRFA**
kathlene.jones@praderwilli.org.au **CEO, PWRFA**
james.obrien@pws.org.au **President, PWSA**
jo.davies@pws.org.nz **CEO and Operations Manager, PWSA NZ**