



5TH  29th to 31st oct 2021  
**ASIAPACIFIC**  
Prader-Willi Syndrome Conference  
*One Voice Together*

**DAY 1 (Friday 29.10.21): FOCUS ON SCIENCE – SPEAKER PROFILES**



*Webinar Technical Team*

**Nadiah Hanim Abdul Latif** is a Strategic Advocacy and Corporate Affairs professional committed to developing effective collaborations that scale for impact. With over 20 years of experience ranging from corporate to NGO and humanitarian work, Nadiah is passionate about issues relating to sustainability, business and human rights, youth empowerment, child rights, protection and development, as well as access to disability resources.

At present, she is a Sustainability & Corporate Affairs consultant, the Co-Founder of social enterprise, OpiS International, a Programme Host with Bernama News Channel, the President of the Malaysian Rare

Disorders Society, the Regional Representative for Southeast Asia, India and South Korea for the Phelan McDermid Syndrome (PMS) Foundation, a member of the Malaysia International Search & Rescue Organisation, an Assistant Child Protector for the Petaling District and a Child Court Advisor for Petaling Jaya.

**Session 1 – Genetics & Development**

**Dr. Duangurdee Wattanasirichaigoon MD** is currently a full professor and chief of the Division of Medical Genetics, Department of Pediatrics, Faculty of Medicine Ramathibodi Hospital, Mahidol University, Thailand. Dr. Duang obtained her MD degree from the Faculty of Medicine, Khon Kaen University and the Board of Pediatrics from Ramathibodi Hospital, and Diploma of the American Board of Medical Genetics (Clinical Genetics and Clinical Molecular Genetics), from the Children's Hospital, Harvard University, Boston, USA. Her research interests are clinical and molecular aspects of rare genetic syndromes, and inborn metabolic disorders. She has been actively involved

in policy advocacy for rare disease management in Thailand, under collaboration between multi stakeholders and National Health Security Office (NHSSO and Ministry of Public Health, since 2011). Dr. Duang is a co-founder of Prader-Willi Syndrome Association of Thailand (2003) and Thai Rare Disease Foundation (ThaiRDF, in 2016).

Dr. Duang has been actively engaged with the annual Thai PWS support group meetings since 2003.



**Session 2 – Endocrinology Care including Growth Hormone**

**Assoc Prof Dr. Muhammad Yazid Yalaludin** is currently the Head of Department of Paediatrics, Faculty of Medicine, University Malaya. He is also a consultant paediatrician and paediatric endocrinologist at the University Malaya Medical Centre who specialise in endocrine and diabetes management in children, and an associate professor at the Faculty of Medicine, University Malaya.

He completed his fellowship in paediatric endocrinology and diabetes at Children's Hospital of Philadelphia, USA after obtaining both his MBBS and Masters in Paediatrics from University Malaya.

He has been a member of various international medical societies, including the Endocrine Society USA and International Society for Paediatric and Adolescent Diabetes.



### Session 3 – Sleep & Breathing in Children with PWS



**Dr. Arun Kumar Pugalenti** graduated from India. He underwent basic and advanced training in general and respiratory paediatrics in the United Kingdom. He subsequently obtained fellowship in paediatric respiratory and sleep medicine at Mater Children's Hospital in Brisbane, Australia. Dr. Arun is currently practicing as a senior consultant in Paediatric Respiratory and Sleep Medicine at KK Women's and Children's Hospital, Singapore.

### Session 4 – Gastroenterology Issues



**Dr. Ann Scheimann MD MBA** received her doctorate of medicine at the University of Cincinnati, School of Medicine and completed her paediatric residency and paediatric gastroenterology and nutrition fellowship at Baylor College of Medicine/Texas Children's Hospital. She was full-time faculty within the Division of Pediatric Gastroenterology and Nutrition at Baylor College of Medicine until 2000 when she moved to join the full-time faculty within the Department of Pediatrics/Division of Pediatric Gastroenterology at Johns Hopkins School of Medicine, but remained adjunct faculty at Baylor College of Medicine directing the Prader-Willi Syndrome Clinic at Texas Children's Hospital.

Dr. Scheimann completed a Masters in Health Sciences Management at Johns Hopkins Carey School of Business in 2005. Dr. Scheimann's focus of research interest has been in nutrition and obesity with special areas of interest in Prader-Willi syndrome and nonalcoholic fatty liver disease. She has authored or co-authored to date more than 80 peer-reviewed publications, in addition to book chapters and meeting presentations.

### Session 5 – Cognition & Mental Health



**Prof Tony Holland** trained in Medicine at University College and University College Hospital, London, qualifying in 1973. In 2002 he was awarded the Health Foundation Chair in Learning (Intellectual) Disability in the Department of Psychiatry at Cambridge University. The multidisciplinary group he led undertook a range of research relevant to people with intellectual disabilities. His clinical work has been as a consultant psychiatrist with specialist learning disabilities services. His specific research interests include the eating, behavioural and mental health problems associated with having Prader-Willi Syndrome. With colleagues he has published research on these topics in academic journals.

Since 2016 he has been President of the International PWS Organisation (IPWSO). In 2010 he was elected a Fellow of the UK Academy of Medical Sciences. In 2015 he was awarded a CBE in the Queen's Birthday Honours for services to psychiatry. Since October 2015 he has held an Emeritus position at the University of Cambridge.

### Session 6 – Healthy Aging

**Dr Susanne Blichfeldt MD** is a paediatrician (paediatric neurology, general and developmental paediatrics). She has more than 30 years of experience working with diagnoses and clinical treatment of children with PWS, and advisor concerning treatment of adults with PWS. She conducted the Scandinavian growth hormone study in children with PWS which resulted in the recommendation of GH for children with PWS in Europe in 2000. Since 1988 she has presented many teaching sessions for caregivers, teachers, parents about PWS in DK and in countries in Europe and presentations about medical issues at PWS and IPWSO conferences.



Susanne is a co-founder of the Danish association 1986, and leader of the advisory board in the association. She is

responsible for publications about PWS for families and professionals in Denmark. She has been Involved in IPWSO (The International PWS Organisation) since 1991; a co-organiser of parent programs for more IPWSO congresses and an IPWSO board member from 2001-2004. She was a member of PPBC, 2010-2014 and is continues to be an advisor in CSAB (IPWSO Clinical and Scientific Advisory Board) since 2004. She is also an associated member of the FAMCARE Committee as a medical advisor.

Susanne is married with children and grandchildren and has a 41year old son has PWS.



## Session 7 – Current Research

**Kathlene Jones**, founder of PWRFA (Prader-Willi Research Foundation of Australia), is mother to a beautiful young girl with Prader-Willi Syndrome and is establishing PWRFA to develop breakthrough treatments that will enable people with Prader-Willi Syndrome to live independent lives. She has extensive experience in management and strategy, having previously worked as General Manager, Strategy at Australia Post and a consultant at McKinsey & Company. Prior to this she worked around the world (London, Beijing, Hong Kong, Sydney) in marketing strategy and research, business development and as an economist.

She has an MBA (Dean's Honours List) from Melbourne Business School and Columbia Graduate School of Business and graduated first in class with a Bachelor of Agricultural Science (Economics) from the University of Queensland. She is now the General Manager of Transformation - Aged Care and Community Services at Uniting Care QLD.



**Dr. Diane Webster** has been with PWRFA since 2016, when she joined the team as the Research Director. In this role she has helped develop and maintain a pipeline of research projects which focusses on real-life outcomes for people with PWS. The Research Program now encompasses two independent projects in epigenetics working to switch on critical PWS genes. Additional workstreams are targeting key symptoms of PWS and core infrastructure such as the Chromosome 15 biobank. We're particularly proud of the role the Foundation plays in supporting clinical trials, both local and international.

## DAY 2 (Saturday 30.10.21): FOCUS ON CARE & SUPPORT – SPEAKER PROFILES

### Session 1 – Dietary Management for People with PWS

**Dr. Roslee Rajikan** is an Associate Professor of Nutrition and Dietetics at the Dietetics Program, Faculty of Health Sciences, Universiti Kebangsaan Malaysia (UKM) and a researcher at the Center for Healthy Aging and Wellness at the same institution. He is also currently the Director for UKM Student Affairs Centre. He also provides dietetics services at the university teaching hospital, Hospital Canselor Tuanku Mukhriz in Cheras, Kuala Lumpur.

He specialises in nutrition and dietetics that focus on clinical nutrition, nutrition for special needs individuals including low income and homeless population, Inborn Error Metabolism, Down Syndrome and Cerebral Palsy, as well as HIV / AIDS, diet optimization modelling

and students development. He earned his BSc in Dietetics (Honours) from UKM, MSc (Nutrition and Metabolism) from the University of Aberdeen and PhD (Nutrition and Plant Science) from the University of Glasgow.



### Session 2 – Physical Therapy

**Assistant Prof Visal Kantaratannakul** is currently a full-time specialist at Rehabilitation Medicine Center at Samitivej Hospital, Bangkok, Thailand. Dr. Visal earned his MD degree from the Faculty of Medicine Siriraj Hospital, Mahidol University and Board of Physical Medicine and Rehabilitation from Faculty of Medicine Ramathibodi Hospital, Mahidol University before he joined the faculty in 1993.

He received certificate in clinical fellowship training from Department of Rehabilitation Medicine, University of Washington at Seattle, USA, and cardiac rehabilitation training course from Heart Research Centre, Melbourne, Australia. Dr. Visal is specialised in exercise in chronic diseases and cardiac rehabilitation. Dr. Visal has been a regular speaker at the annual meetings held by Prader-Willi Syndrome Association of Thailand since 2012.

### Session 3 – Speech Therapy for Improved Communications

**Hayley Arnott** is a speech-language therapist working for the Ministry of Education in Tauranga, New Zealand. She works with children over 2 years of age with a range of communication and developmental difficulties. She is also mum to three children, the youngest of which is five years old Josie, who has Prader-Willi syndrome.



### Session 4 – Personal Development Record



**Dr Satoko Nakagomi** is a Professor at Shinshu University School of Health Sciences Division of Nursing. Her specialty is genetic/genomics nursing and counseling, and women's health and midwifery. She has been a member of PWSA Japan since 2010 and is a board member as a professional. Her activity with PWSA Japan includes attending the caregiver conference in Germany and distributing the translated Best Practice book in Japan, as well as giving numerous lectures for the members. She is involved in the creation of "PWS Record Book," which is created to support the everyday life of children with PWS and their families, and to be connected with surrounding supporting organisations. It has been developed with collaborative effort together with the family of children with PWS and caregivers.



**Assoc Prof Noriko SASAKI** is a midwife and genetic counsellor from the Department of Reproductive Health Institute of Biomedical Sciences Nagasaki University. She has been a member of PWSA Japan since 2013. She has so far conducted an investigation into the health management of children with PWS at school age, a survey investigation on communication between parents of children with PWS and home room teachers, as well as an interview survey with adult people with PWS.

She is involved in implementing an early genetic education program for infants and elementary school students. Through this activity, the aim is to educate children in the "diversity" and "uniqueness" of individuals and that everyone is an only one of important existence.

### Session 5 – Enabling a Full Life

**Dr. John Ford** is a psychologist and positive behaviour for learning practitioner from the New Zealand Ministry of Education. He has spent more than 30 years working in various roles to support children and adults with disabilities whose behaviour presents challenges to themselves or others. He loves to support people with PWS, and he is especially interested in the ways families and professional caregivers find to resolve the challenges they face.

John lives in Wellington, New Zealand where he works to help schools develop policies and practices that reduce behavioural challenges and promote learning and engagement among students.

In 2018, John completed a thesis titled "Supporting adults who have Prader-Willi syndrome: caregivers' perspectives on the ethical and practical dilemmas" for the degree of Doctor of Philosophy in Psychology at Massey University, Wellington.



## Session 6 – Behavioural Management & Residential Support

**Dr Norbert Hodebeck-Stuntebeck** is a psychologist, psychotherapist and a supervisor, who resides in Bad Oeynhausen, Germany, where he currently serves as Project Manager Prader-Willi-Syndrome and Projektmanager Adipositas (Obesity) for Diakonische Stiftung Wittekindshof (a Lutheran foundation in the north west of Germany, in Northrhine-Westfalia). He received his PhD in 2012 at the University of Eichstätt by a study about the competence of people with Prader-Willi syndrome in change of perspective (empathy).



Since 1996 he has been responsible for the development and differentiation of support for people with PWS of all ages and in different fields of living, working, school and training programs.

His interest in research is focused on empathy (change of perspective) in PWS and the development and evaluation of training programs. Another field of interest is obesity in people with learning disabilities.

## Session 7 – Residential Services in New Zealand



**John Taylor** is the Executive Director of Community Connections – Te Hapori Awhina Tangata, a community-based disability service which primarily offers a Supported Living service, with some Residential Services as well. Community Connections have a strong commitment to a person-centered approach so people can live the life they choose within their own community. They aim to provide the natural supports necessary for a person to live in their own home, to connect with their community and to enjoy an independent, fulfilling life. John has been involved in the disability sector in New Zealand for around 35 years. He has worked in a variety of roles including direct service, operational management, policy formation, political lobbying, governance, advocacy, organisational development, training, and consultancy.

John is also a member of the National Leadership Group for Enabling Good Lives and is on the board of NZDSN (New Zealand Disability Support Network).



**Cindy Adams-Vining** has been involved in the work of PWSA New Zealand since its early days. Cindy has a family support role and has worked as Training Manager for the last 10 years. In her work, Cindy delivers PWS training to service provider organisations across New Zealand and also meets with many adults with PWS. Cindy also provides social connection for adults with PWS and has been instrumental in the establishment of the PWSA NZ's 'Adults with PWS Leadership Group'.

Cindy has also been a committee member for IPWSO, worked for SAMS (Standards and Monitoring Services) providing Developmental Evaluation services to improve community services for people with a disability, has worked as a training facilitator for Care Matters NZ, and is the coordinator of Special Olympics Marlborough.

## Session 8 – Residential Services in Australia

**Mr Damien Jones** has worked as a cluster manager for Interaction Disability Services (Interaction) since 2006. Interaction established Australia's first accommodation model specifically for adults with PWS in 1992 and now operates four houses for people with PWS. Interaction also provides behaviour management, training and individualised options for people with PWS. Having worked at multiple levels, supporting people with PWS, Damien brings a unique perspective and insight into their needs.

Damien has delivered training and numerous workshops on PWS and has contributed to IPWSO's Famcare articles. Damien is a member of the Professional Providers and Caregivers Board' (PPCB) of IPWSO and assists in organising international conferences for people with PWS.





## Session 9 – IPWSO Role and Support

**Mr. James O' Brien** is the Vice-President, International Prader-Willi Syndrome Organisation (IPWSO) and the President of Prader-Willi Syndrome Association of Australia. James has a powerful desire to maximise outcomes for all people living with PWS. James' education, management and operating experience spans national and international charities, special school settings and disability services.

James holds numerous volunteer appointments, including: Director, International Prader-Willi Syndrome Organisation; Council Member, RADE Global Advocacy Leadership Council, Global Genes; President, Prader-Willi Syndrome Australia; Founding Director, PWS Better Living Foundation.

James' love for his two children, including his son Ashley (26 years old) living with PWS, drives his desire to establish PWS education, advocacy and support services across Australia and around the globe.

### DAY 3 (Sunday 31.10.21): HEAR OUR VOICES

Our Day 3 programme is focused on providing an insight into the lives of people living with PWS and will feature presentations by parents, children and adults living with PWS from all four organising countries (Malaysia, Australia, New Zealand, Thailand), plus contributions from other Asia Pacific countries. This is a new initiative aimed at 'giving a voice' to the people we support, as well as furthering understanding, or providing hope and inspiration.

#### New Beginnings – Parents' stories: diagnosis and early days

#### The Start of our Journey (0-6yrs) – Families living with PWS

#### A Day in the Life of (6-12yrs) – Voices of our children living with PWS

#### I'm Growing Up – Voices of our adolescents living with PWS

#### My Story – Life experience stories shared by adults living with PWS

#### Living Options – A glimpse into supported living / residential care possibilities

#### Friendships Beyond Borders – Adults with PWS engaging in international discussion

#### May I Ask you a Question? – 'Live' panel discussion: people with PWS to answer questions

✉ [appws2021@gmail.com](mailto:appws2021@gmail.com)

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