

11th International Prader-Willi Syndrome Conference 2022

Professional Providers and Caregivers Conference



Day 1: Thursday 7 July 2022

FGO42, FBO28, UCH & John Holland Theatre, Main Building

08:30-09:00	Welcome and introduction to conference: FGO42 Lynn Garrick, IPWSO Professional Providers and Caregivers Board (PPCB) Chair, and Laura Keane, IPWSO PPCB Co-Chair, Marguerite Hughes, IPWSO Chief Executive Officer; Anthony Carr, Chairperson PWSAI, and Johannes Fuhrmann, Germany		
Session 1	Overview of PWS Services in Different Countries	Session chair: Norbert Hödebeck-Stuntebeck	
	In this session we will take a trip across the globe and learn about the availability, or otherwise, of services for people living with PWS. We'll gain insights about resources and approaches to care and behaviour management.		
09:00-09:15	Columbia María Elvira García Ronderos, Presidente, Asociación Colombiana Síndrome de Prader-Willi, Columbia Following the video presentation Johana Rocha from Asociación Colombiana Síndrome de Prader-Willi will be available for in-person Q&A.		
09:15-09:30	Ireland Gary Brennan, National Development Manager, PWSAI, Ireland		
09:30-09:45	Malaysia Lantz Yap, PWS Association, Malaysia		
09:45-10:00	The Netherlands Fred Nicolai, Chairman Prader-Willi Stichting, The Netherlands		
10:00-10:15	Russia Marina Verbivskaya, Parent, Founder and Head of PWS Association, Russia		
10:15-10:30	South Africa Karin Clarke, Chairperson PWS Support Group, South Africa		
10:45-11:15	Break		
	Keynote Speech	Introduction by Laura Keane	
11:15-11:30	Anne Rabbitte, T.D., Minister of State at the Department of Children, Equality, Disability, Integration and Youth and Department of Health with special responsibility for Disabilities, Ireland		
Session 2	Wellbeing	Session chair: Mary K. Ziccardi	
11:30-11:45	Video presentations: What does Wellbeing mean to people with PWS? We asked people with PWS to share their fears, and their dreams for the future.		
11:45-12:15	5 Points of Wellbeing: What this means to people with PWS Norbert Hödebeck-Stuntebeck, PhD, PWS-InterNational, Germany		
12:15-12:30	Everyday challenges of families of children living with Prader-Willi Syndrome in Hungary Zsófia Gács, Semmelweis University, 2nd Department of Pediatrics, Budapest, Hungary		
12:30-13:45	Lunch – Poster session		
Session 3	Workshop: Restrictive Practice	Session chair: Hubert Soyer	
13:45-14:15	Prader-Willi Syndrome (PWS) and Restrictive Practice Hubert Soyer, PhD., Psychologist, Germany		
14:15-15:00	Breakout group 1 - FGO42 Team leaders: Patrice Carroll, Norbert Hödebeck-Stuntebeck and Mary K. Ziccardi	Breakout Group 2 – FB028 Team leaders: Lynn Garrick Hubert Soyer	Breakout Group 3 – John Holland Theatre Team leaders: Larry Genstil, Laura Keane and Jackie Mallow
15:00-15:30	Break		
Session 3	Workshop: Restrictive Practice (continued) - FGO42	Session chair: Hubert Soyer	
15:30-17:30	Developing a Restrictive Practice Model		

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Day 2: Friday 8 July 2022 FG042 - UCH

Session 1	Behaviour	Session chair: Hubert Soyer
08:30-08:50	Behaviour and Mental Health Tony Holland, University of Cambridge, UK, and President of IPWSO	
08:50-09:10	Intensive or Challenging Care Norbert Hödebeck-Stuntebeck, IPWSO PPC Board Member, PWS-InterNational, Germany	
09:10-09:30	Telehealth Program with Caregivers to Manage Behavioural Disorders Dr Jorge La Serna, Asociación Colombiana Síndrome de Prader-Willi, Colombia	
09:30-09:50	Proactive and Reactive Behavioural Risk Management in Residential Services Supporting Adults with Prader-Willi Syndrome (PWS): A Functional Resonance Analysis Method (FRAM) Study Kevin Hoy, Head of Quality and Risk, Resilience Healthcare, Ireland	
09:50-10:10	Causes of Behaviour and How to Respond Patrice Carroll, Director of PWS Services, and Brittni Kliment, Director of Program Marketing and Admissions, Latham Centers, USA	
10:10-10:30	Q&A	
10:30-11:00	Break	
Session 2	Round Table: Independence	Session chairs: Norbert Hödebeck-Stuntebeck and Hubert Soyer
11:00-11:15	Presentation: People with PWS give their views on Independence	
11:15-12:15	Round table discussion - moderated by Norbert Hödebeck-Stuntebeck and Hubert Soyer Joan Gardner, USA Parent Representative to IPWSO Lynn Garrick, Chair, IPWSO Professional Providers and Caregivers Board (PPCB), USA Larry Genstil, IPWSO PPC Board Member, Israel Marguerite Hughes, IPWSO Chief Executive Officer, Ireland Constanze Lämmer, Senior Physician, Children's Hospital, St. Bernward Hospital, Hildesheim, Germany Jennifer Miller MD, Director of the UF Health PWS Program, USA Lesley Robertson, IPWSO Famcare Board Member, Australia	
12:15-12:30	Summary of discussion Patrice Carroll, Director of PWS Services, Latham Centers, USA	
12:30-13:30	Lunch	
Session 3	Social Media	Session chair: Lynn Garrick
13:30-13:50	Social Media: Friend and Foe Lynn Garrick, Chair, IPWSO Professional Providers and Caregivers Board, Programme Director, AME Community Services, USA	
13:50-15:00	Social Media: Friend and Foe	
15:00-15:30	Break	
Session 4	Living options for people with PWS	Session chair: Laura Keane
15:30-16:00	Preliminary findings from data on residential services for people with PWS Brian Hughes, Professor of Psychology, National University of Ireland, Galway, and Member of IPWSO's Advisory Group on Research on Specialist Services for People with PWS, Ireland	
16:00-16:30	Smart Homes Patrice Carroll, Director of PWS Services, and Lee Chamberlain, Vice-President – Operations, Latham Centers, USA	
16:30-17:00	Designing Optimum Models for Living – Open Floor Discussion led by Laura Keane	
Session 5	Plenary	
17:00-17:30	Summary of Professional Providers and Caregivers Conference Lynn Garrick, IPWSO Professional Providers and Caregivers Board Chair, and Laura Keane, IPWSO PPCB Co-Chair	

Please note: The Conference Planning Committee reserve the right to amend the content and timings of the programme, if deemed necessary.