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

and Laura Keane, IPWSO PPCB Co-Chair, Marquerite Hughes, IPWSO Chief Executive Officer, Anthony Carr, Chairperson PWSAI, and Johannes Fuhrmann, Germany Session 1 Overview of PWS Services in Different Countries 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. Columbia Maria Elvira Garcia Ronderos, Presidente, Asociación Columbiana Sindrome de Prader-Willi, Columbia Following the video presentation Johana Rocha from Asociación Columbiana Sindrome de Prader-Will will be available for in-person Q&A. Ireland Gary Brennan, National Development Manager, PWSAI, Ireland Malaysia Lantz Yap, PWS Association, Malaysia 10:945-10:00 The Netherlands Fred Nicolai, Chairman Prader-Willi Stichting, The Netherlands Russia Marina Verbivskaya, Parent, Founder and Head of PWS Association, Russia 10:15-10:30 South Africa 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 Wellbeing What does Wellbeing mean to people with PWS Norbert Hödebeck-Stuntebeck, PhD, PWS-InterNational, Germany Everyday challenges of families of children living with Prader-Willi Syndrome in Hungary 2söfia Gäcs, Semmelweis University, 2nd Department of Pediatrics, Budapest, Hungary 12:15-12:30 Prader-Willi Syndrome (PWS) and Restrictive Practice Hubert Soyer, PhD, Psychologist, Germany 14:15-15-10 Break Workshop: Restrictive Practice (continued) - FG042 Session and Jackie Mallow 15:30-17:30 Developing a Restrictive Practice Model	08:30-09:00	Welcome and introduction to conference: FG042 Lynn Garrick, IPWSO Professional Providers and Caregivers Board (PPCB) Chair,			
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Team leaders: Patrice Carroll, Team leaders: Lynn Garrick Norbert Hödebeck-Stuntebeck Hubert Soyer and Mary K. Ziccardi 15:00-15:30 Break Session 3 Workshop: Restrictive Practice (continued) - FG042 Session chair: Hubert Soyer		·	•		
Norbert Hödebeck-Stuntebeck Hubert Soyer and Jackie Mallow and Mary K. Ziccardi 15:00-15:30 Break Session 3 Workshop: Restrictive Practice (continued) - FG042 Session chair: Hubert Soyer	14:15-15:00	<u> </u>	<u> </u>	<u> </u>	
and Mary K. Ziccardi 15:00-15:30 Break Session 3 Workshop: Restrictive Practice (continued) - FG042 Session chair: Hubert Soyer		•	•		
15:00-15:30 Break Session 3 Workshop: Restrictive Practice (continued) - FG042 Session chair: Hubert Soyer			Hubert Soyer	and Jackie Mallow	
Session 3 Workshop: Restrictive Practice (continued) - FG042 Session chair: Hubert Soyer					
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15:30-17:30 Developing a Restrictive Practice Model					
	15:30-17:30	Developing a Restrictive Practice	NIOGE		

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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		
03.50-10.10	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 Garrich		
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-Cha		

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