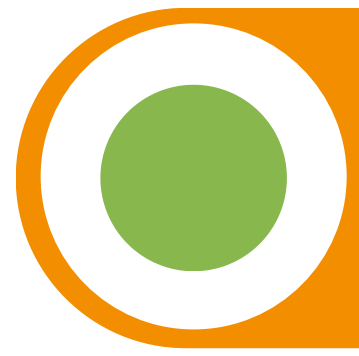


Day 1: Tuesday 21 May 2024

	Opening and welcome	Room: Conference 1+2
09:00-09:30	Dr Andreas Eckhoff, CEO of EJF gemeinnützige AG, Germany Tony Holland, IPWSO President, University of Cambridge, UK Lynn Garrick, Chair of the IPWSO Professional Providers and Caregivers Board (PPCB), USA, and Hubert Soyer, PPCB Member, Germany	
09:30-09:45	Video: Thank you, caregivers! People with PWS from around the world	
09:45-10:15	Pam Eisen Lecture: The future of care for people with PWS Norbert Hödebeck-Stuntebeck, PhD, PWS-InterNational, Germany	
10:15-10:45	Break	
10:45-11:15	IPWSO's initiative to give people with PWS a voice Svetlana Labun, Managing Director, EJF Hollerhaus gGmbH, Trustee, IPWSO, Germany People with PWS give themselves a voice: Requirements and solutions (example of a group in Germany) Christian Blohm, Metalworker, Germany	
11:15-11:30	Outcomes for persons with Prader-Willi syndrome in full-time services: Findings from international archival data and future research directions Brian Hughes, Professor of Psychology, University of Galway, Ireland	
11:30-11:45	Operationalised list of infrastructure and staff skills required for specialised care of PWS as rated by residential care providers in the USA Janice Forster, MD, Board Certified General and Child and Adolescent Psychiatrist in private practice in Pittsburgh PA, USA	
11:45-12:00	Service involvement for children seen in the specialist PWS child mental health service in UK: Supporting a multi-agency approach to food security and wellbeing (and how restrictions can be liberating) Dr Sarah Carman, National and Specialist CAMHS Specialist Prader Willi Syndrome Service, Mental Health of Intellectual Disabilities Team, SCAAND, Michael Rutter Centre, South London and Maudsley NHS Foundation Trust, UK	



Day 1: continued

12:00-12:15 **Introduction to the poster presentations and afternoon workshops**
Laura Keane, Co- Chair of the IPWSO Professional Providers and Caregivers Board, Chief Executive, Resilience Healthcare, Ireland

12:15-13:15 Lunch break

13:15-13:45 **Poster presentations** **Room: Conference hall**
Moderated by: Laura Keane, Chief Executive, Resilience Healthcare, Ireland

13:45-15:30	Workshop: Art as a therapeutic approach for people with PWS Room: Conference 4 Led by: Tovi Florsheim	Workshop: Balancing rights and restrictions for individuals with PWS Room: Conference 1 Led by: Hubert Soyer, Gary Brennan, Lynn Garrick	Workshop: Friends, partnerships and sexuality Room: Conference 2 Led by: Patrice Carroll, Neil Gumley	Workshop: Understanding behaviour Room: Conference 5 Led by: Norbert Hödebeck-Stuntebeck, Tony Holland
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15:30-16:00 Break

16:00-17:45	Therapy options: Art (continued)	Balancing rights and restrictions (continued)	Friends, partnerships and sexuality (continued)	Understanding behaviour (continued)
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17:45 End of day

Day 2: Wednesday 22 May 2024

09:00-10:30	Therapy options: ABA (continued) Led by: Vikacha Phiri	Balancing rights and restrictions (continued)	Friends, partnerships and sexuality (continued)	Understanding behaviour (continued)
10:30-11:00	Break			
11:00-11:30	Overview of the Clinical Trials Process Nathalie Kayadjanian, Ph.D. Scientific advisor, Raymond A. Wood Foundation, Trustee, IPWSO, USA			Room: Conference 1+2
11:30-12:30	Research and Clinical Trials Updates Santiago Figueroa Pérez, COO, Palobiofarma, Spain June Sanson, Executive Director of Patient Advocacy & Industry Relations, Acadia Pharmaceuticals, USA Dr. Dairine Dempsey, VP, Europe, Soleno Therapeutics Inc., Ireland Moderated by: Tony Holland, IPWSO President, University of Cambridge, UK			
12:30-13:30	Lunch break			
13:30-15:15	Workshop: Ageing Room: Conference 4 Led by: Susanne Blichfeldt, Larry Genstil	Workshop: Staff retention: and what happens when there is a breakdown? Room: Conference 1 Led by: Lynn Garrick, Claire Poor-Harmon	Workshop: Friends, partnerships and sexuality (repeated) Room: Conference 2 Led by: Patrice Carroll, Neil Gumley	Workshop: Understanding behaviour (repeated) Room: Conference 5 Led by: Norbert Hödebeck-Stuntebeck, Tony Holland
15:15-15:45	Break			
15:45-17:00	Ageing (continued)	Staff retention (continued)	Friends, partnerships and sexuality (continued)	Understanding behaviour (continued)
17:00-19:00	Break			
19:00-23:00	Conference dinner			Room: Conference 1+2

Day 3: Thursday 23 May 2024

09:00-10:30	Ageing (continued)	Staff retention (continued)	Friends, partnerships and sexuality (continued)	Understanding behaviour (continued)
10:30-11:00	Break			
11:00-11:30	Meaningful employment for people with PWS Larry Genstil, Psychologist, Israel		Room: Conference 1+2	
11:30-11:45	Network Switzerland Bastian Bühler, Social educator/Team leader, Stiftung Arkadis, Switzerland			
11:45-12:00	PWS Competence Center Austria Janine Sinner, Team Leader, Caritas Upper Austria, Austria			
12:00-13:30	Lunch break			
13:30-14:15	Panel discussion: Self-determination, self-control: Opportunities and limitations Lee Chamberlain, VP & Chief Strategy Officer, Latham Centers, Inc., USA Maria Kirby, Clinical Services Manager, Resilience Healthcare, Ireland Fred Nikolai, Chairman Prader-Willi Stichting, The Netherlands Michelle Torbert, President, Friends of IPWSO (USA), USA Moderated by: Hubert Soyer, Psychologist, Germany			
14:15-15:00	Questions and Answers: Your medical questions David M. Agarwal, MD, FSIR, Indiana University School of Medicine, USA Susanne Blichfeldt, MD, The Danish Prader-Willi Association, IPWSO Clinical and Scientific Advisory Board (CSAB), Denmark Janice Forster, MD, Developmental Neuropsychiatrist, Pittsburg Partnership, Pittsburgh, PA, USA Moderated by: Lynn Garrick, Programme Director, AME Community Services, USA			



Day 3: continued

Panel discussion: **What supports are available for people with PWS who overburden the system with their challenging behaviour? Models and limits**

15:00-15:45

Patrice Carroll, Director of PWS Services, Latham Centers, USA
Lynn Garrick, Programme Director, AME Community Services, USA
Larry Genstil, Psychologist, Israel
Myles Kelly, Project Manager, PWSA UK, UK

Moderated by: Norbert Hödebeck-Stuntebeck, PhD, PWS-InterNational, Germany

Close and thank you

15:45-16:15

Lynn Garrick, Chair of the IPWSO Professional Providers and Caregivers Board, and Laura Keane, Co- Chair

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

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