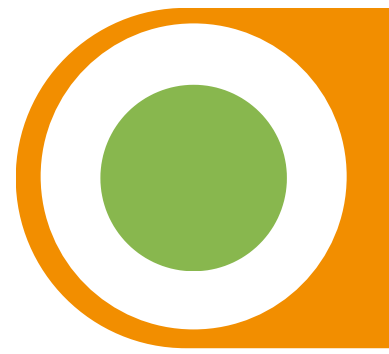


## Day 1: Tuesday 21 May 2024

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	<b>Opening and welcome</b>	<b>Room: Conference 1+2</b>
09:00-09:30	Lynn Garrick, Chair of the IPWSO Professional Providers and Caregivers Board (PPCB), USA, and Hubert Soyer, PPCB Member, Germany Tony Holland, IPWSO President, University of Cambridge UK	
09:30-09:45	Video: <b>Thank you, caregivers!</b> People with PWS from around the world	
09:45-10:15	Pam Eisen Lecture: <b>The future of care for people with PWS</b> Norbert Hödebeck-Stuntebeck, PhD, PWS-InterNational, Germany	
10:15-10:45	Break	
10:45-11:15	<b>IPWSO's initiative to give people with PWS a voice</b> Svetlana Labun, Managing Director, Hollerhaus gGmbH, Trustee, IPWSO, Germany <b>Give people with PWS a voice: Demands and solutions (example of a group in Germany)</b> Christian Blohm, Metalworker, Germany	
11:15-11:30	<b>Outcomes for persons with Prader-Willi syndrome in full-time services: Findings from international archival data and future research directions</b> Brian Hughes, Professor of Psychology, University of Galway, Ireland	
11:30-11:45	<b>Operationalised list of infrastructure and staff skills required for specialised care of PWS as rated by residential care providers in the USA</b> Janice Forster, MD, Board Certified General and Child and Adolescent Psychiatrist in private practice in Pittsburgh PA, USA	
11:45-12:00	<b>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)</b> 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

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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

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12:15-13:15 Lunch break

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13:15-13:45 **Poster presentations** **Room: Conference hall**

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

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

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# Day 2: Wednesday 22 May 2024

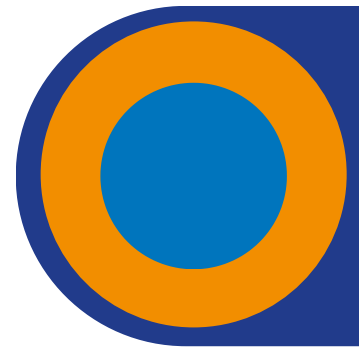
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09:00-10:30	<b>Therapy options: ABA (continued)</b> Led by: Vikacha Phiri	<b>Balancing rights and restrictions (continued)</b>	<b>Friends, partnerships and sexuality (continued)</b>	<b>Understanding behaviour (continued)</b>
10:30-11:00	Break			
11:00-11:30	<b>Overview of the Clinical Trials Process</b> Nathalie Kayadjanian, Ph.D. Scientific advisor, Raymond A. Wood Foundation, Trustee, IPWSO, USA		<b>Room: Conference 1+2</b>	
11:30-12:30	<b>Research and Clinical Trials Updates</b> 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 <b>Moderated by:</b> Tony Holland, IPWSO President, University of Cambridge, UK			
12:30-13:30	Lunch break			
13:30-15:15	Workshop: <b>Aging</b>  <b>Room: Conference 4</b> Led by: Susanne Blichfeldt, Larry Genstil	Workshop: <b>Staff retention: and what happens when there is a breakdown?</b>  <b>Room: Conference 1</b> Led by: Lynn Garrick, Claire Poor-Harmon	Workshop: <b>Friends, partnerships and sexuality (repeated)</b>  <b>Room: Conference 2</b> Led by: Patrice Carroll, Neil Gumley	Workshop: <b>Understanding behaviour (repeated)</b>  <b>Room: Conference 5</b> Led by: Norbert Hödebeck-Stuntebeck, Tony Holland
15:15-15:45	Break			
15:45-17:00	<b>Aging (continued)</b>	<b>Staff retention (continued)</b>	<b>Friends, partnerships and sexuality (continued)</b>	<b>Understanding behaviour (continued)</b>
17:00-19:00	Break			
19:00-23:00	<b>Conference dinner</b>		<b>Room: Conference 1+2</b>	

# Day 3: Thursday 23 May 2024

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09:00-10:30	<b>Aging (continued)</b>	<b>Staff retention (continued)</b>	<b>Friends, partnerships and sexuality (continued)</b>	<b>Understanding behaviour (continued)</b>
10:30-11:00	Break			
11:00-11:30	<b>Meaningful employment for people with PWS</b> Larry Genstil, Psychologist, Genstil Institute of Human Behaviour, Israel			<b>Room: Conference 1+2</b>
11:30-11:45	<b>Network Switzerland</b> Bastian Bühler, Social educator/Team leader, Stiftung Arkadis, Switzerland			
11:45-12:00	<b>PWS Competence Center Austria</b> Janine Sinner, Team Leader, Caritas Upper Austria, Austria			
12:00-13:30	Lunch break			
13:30-14:15	Panel discussion: <b>Self-determination, self-control: Opportunities and limitations</b> Participants TBA shortly <b>Moderated by:</b> Hubert Soyer, Psychologist, Germany			
14:15-15:00	Questions and Answers: <b>Your medical questions</b> 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 <b>Moderated by:</b> Lynn Garrick, Programme Director, AME Community Services, USA			



## Day 3: continued

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Panel discussion: **What supports are available for people with PWS who overburden the system with their challenging behaviour? Models and limits**  
Patrice Carroll, Director of PWS Services, Latham Centers, USA  
15:00-15:45 Lynn Garrick, Programme Director, AME Community Services, USA  
Larry Genstil, Psychologist, Genstil Institute of Human Behaviour, Israel  
Myles Kelly, Project Manager, PWSA UK, UK  
Maria Kirby, Clinical Services Manager, Resilience Healthcare, Ireland  
**Moderated by:** Laura Keane, Chief Executive, Resilience Healthcare, Ireland

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**Close and thank you**  
15:45-16:15 Lynn Garrick, Chair of the IPWSO Professional Providers and Caregivers Board, and Laura Keane, Co- Chair

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