

IPWSO's 10th International Conference, Havana, Cuba

Professional Providers' and Caregivers' programme: 14th to 15th November 2019

Updated on 11th September 2019

Thursday 14th November

08.00 – 08.30	Registration
08.30 – 10.00	Session 1: Opening and overview about special provisions and services for PWS in different countries
08.30 – 08.45	<i>Welcome, Opening and Greetings</i> Norbert Hödebeck-Stuntebeck, Chair of the Professional Providers and Caregivers Board of IPWSO, Diakonische Stiftung Wittekindshof and Prader-Willi Syndrome Institute Germany Tony Holland, IPWSO President and University of Cambridge, UK
08.45 - 09.00	<i>Overview Cuba</i> Raiza Parés Ojeda, University of Ciego de Avila, Cuba
09.00 – 09.15	<i>Overview Australia</i> Craig Moore, Interaction, Australia
09.15 – 09.30	<i>Overview Argentina</i> Jorgelina Stegmann, SPINE Foundation, Argentina
09.30 – 09.45	<i>Overview Ireland</i> Laura Keane, Resilience Care, Ireland
09.45 – 10.00	<i>Overview Japan</i> Yoshiro Kato, Kansai University of Welfare Sciences, Japan Takayuki Kido, "ikiiki" non-profit organisation, Japan Yasunobu Yamada, Residential Rehabilitation Institution "Teran Hiroba", Social Service Organisation "Doyukai", Japan
10.00 – 10.30	Break
10.30 – 12.00	Session 2: Early Intervention
10.30 – 10.35	<i>Introduction</i> Norbert Hödebeck-Stuntebeck, Diakonische Stiftung Wittekindshof, Germany
10.35 – 10.50	<i>Main challenges in adults with PWS</i> Norbert Hödebeck-Stuntebeck, Diakonische Stiftung Wittekindshof, Germany
10.50 – 11.15	<i>Physical Development</i> Constanze Lämmer, Children's Hospital St. Bernward, Germany
11.15 – 11.40	<i>Cognitive, emotional, social development</i> Norbert Hödebeck-Stuntebeck, Diakonische Stiftung Wittekindshof, Germany
11.40 – 12.00	<i>Parents and Environment</i> Constanze Lämmer, Children's Hospital St. Bernward, Germany
12.00 – 13.00	Lunch
13.00 – 14.30	Session 3: PWS and Aging
13.00 – 13.30	<i>Medical aspects of aging</i> Larry Genstil, Genstil Institute of Human Behaviour, Israel
13.30 – 14.00	<i>Emotional aspects of aging</i> Larry Genstil, Genstil Institute of Human Behaviour, Israel Damien Jones, Interaction, Australia
14.00 – 15.00	<i>Social aspects of aging</i> Damien Jones, Interaction, Australia
14.30 – 15.00	Break
15.00 – 17.00	Session 4: Handling crisis situations and challenging behaviour

15.00 – 15.10	<i>Systemic view</i> Norbert Hödebeck-Stuntebeck , Diakonische Stiftung Wittekindshof, Germany
15.10 – 15.30	<i>Legal basics and ethics</i> Anna Murray, University of Cambridge, UK
15.30 – 16.00	<i>Prevention</i> Svetlana Labun, Regens Wagner Absberg, Germany Norbert Hödebeck-Stuntebeck , Diakonische Stiftung Wittekindshof, Germany
16.00 – 16.30	<i>Handling</i> Michael Pethe, Head of Department and Deputy Home Director at two PWS residential groups in Graubünden, Switzerland
16.30 – 17.00	<i>Reflection: Concrete support within a Rogerian practice framework</i> Christine Ford, Community Connections, New Zealand Geoff Kelly, Community Connections, New Zealand

Friday 15th November

08.00 – 08.30	Registration
08.30 – 10.00	Session 5: People with PWS at home - Family support
08.30 – 09.00	<i>Basics for families</i> Marguerite Hughes, Vice-President, IPWSO
09.00 – 09.20	<i>Model of a specialist mental health / behavioural service</i> Natasa Momcilovic, Maudsley Hospital, London, UK
09.20 – 09.40	<i>Nutrition in a family environment</i> Constanze Lämmer, Children's Hospital St. Bernward, Germany
09.40 – 10.00	<i>Physical exercise in a family environment</i> Georgina Loughnan, Prader-Willi Syndrome Clinic, Royal Prince Alfred Hospital, Australia
10.00 – 10.30	Break
10.30 – 11.15	Session 6: Teachers' world
10.30 – 11.15	<i>Issues with teaching people with PWS in the classroom</i> Larry Genstil, Genstil Institute of Human Behaviour, Israel
11.15 – 12.00	Session 7: Neuropsychology in PWS
11.15 – 12.00	<i>A Neuropsychological view of PWS</i> Hubert Soyer, Regens Wagner Absberg, Germany Svetlana Labun, Regens Wagner Absberg, Germany
12.00 – 13.00	Lunch
12.30 – 13.00	Poster presentations
13.00 – 14.30	Session 8: Science and Research
13.00 – 13.45	<i>Overview about themes in research for PWS</i> Tony Holland, University of Cambridge, UK
13.45 – 14.00	<i>Current and planned future clinical trials</i> Nathalie Kayadjanian, Foundation for Prader-Willi Research, USA
14.00 – 14.15	<i>Study TBC</i>
14.15 – 14.30	<i>Study TBC</i>
14.30 – 15.00	Break
15.00 – 16.45	Session 9: New Developments
15.00 – 15.20	<i>Standards - how to develop first ideas</i> Laura Keane, Resilience Care, Ireland
15.20 – 15.40	<i>Developing summer camps for people with PWS</i> Djanik Gade Andersen, Central Denmark Region Jannik Sayoudi, PWS-Bostedet Kirstinelund, Denmark
15.40 – 16.00	<i>Developments in PWS in Austria</i> Stefan Pimmingstorfer, Caritas für Menschen mit Behinderungen/ Caritas Upper Austria
16.00 – 16.20	<i>Supporting health situations in Fejo, Denmark</i> Karin Birkedal, Bostedet Solvang ApS, Denmark Trine Jensen, Bostedet Solvang ApS, Denmark Christina Brydegaard, Bostedet Solvang ApS, Denmark
16.20 – 16.45	<i>Transition – the role of the endocrine nurse</i> Maria Pedersen, Karolinska University Hospital, Sweden
16.45 – 17.00	Session 10: Summary and perspective Norbert Hödebeck-Stuntebeck, Diakonische Stiftung Wittekindshof