

IPWSO's 10th International Conference, Havana, Cuba

Parents' programme: 16th to 17th November 2019

Updated on 19th September 2019

The conference will be held in the Theatre

Saturday 16th November

08.30 – 09.00	Registration	
09.00 - 09.15	Opening from the Chair Amalia Balart, Conference chair and Board member of IPWSO, Chile Tony Holland, President of IPWSO, University of Cambridge, UK	
09.15 - 09.45	Overview of PWS Dan Driscoll, MD, University of Florida College of Medicine, USA	
9.45 – 10.30	The changing face of PWS – progress and the future Jennifer Miller, MD, University of Florida, USA	
10.30 – 11.00	Break	
11.00 – 11.30	Chair: James O'Brien, Board member of IPWSO, Australia Living with PWS / Parents and people with PWS Amalia Balart, Board member of IPWSO, Chile, Board Member of PWS Association in Chile, Master in Special Education for learning disabilities. Verena Gutmann, Educational Head of Department, Austria	
11.30 – 12.30	Essential communication skills for families Linda Gourash, MD, Pittsburgh Partnership, USA	
12.30 – 13.30	Lunch	
13.30 – 14.00	Chair: Verena Gutmann, Board member of IPWSO, Austria Orthopaedic Issues Harold van Bosse, MD, Shriners Hospital for Children, USA	
14.00 – 14.30	Room 1 Theatre - Early development and growth hormone Chair: Verena Gutmann, Board member of IPWSO, Austria Children 0 to 18yrs Constanze Lämmer, Children's Hospital St. Bernward, Germany	Room 2 Vilma Espín - Adolescent and adulthood endocrinology Chair: Georgina Loughnan, Board member of IPWSO, Australia Adolescents and adults Charlotte Höybye, Karolinska University Hospital and Karolinska Institute, Sweden
14.30 – 15.00	Break	

<p>15.00 – 16.30</p> <p>Lectures followed by Workshops</p>	<p>Room 1 Theatre - Children 0 to 12yrs</p> <p>Chair: Verena Gutmann, Board member of IPWSO, Austria</p> <p>Healthy start to life:</p> <p>Nutrition Paulina Bravo, Clinica Santa Maria and Universidad de los Andes, Chile</p> <p>Physical activity Daniela Rubin, California State University, Fullerton, USA</p>	<p>Room 2 Vilma Espín - Children 13yrs to adult</p> <p>Chair: Georgina Loughnan, Board member of IPWSO, Australia</p> <p>Healthy maturation and lifestyle:</p> <p>Physical activity Daniela Rubin, California State University, Fullerton, USA</p> <p>Nutrition Paulina Bravo, Clinica Santa Maria and Universidad de los Andes, Chile</p> <p>Healthy ageing Susanne Blichfeldt, The Danish Prader Willi Association and Centre for Rare Diseases, Denmark</p>
<p>16.30 – 17.00</p>	<p>Chair: Marguerite Hughes, Vice-President of IPWSO, Ireland</p> <p>Current research and clinical trials in PWS Jennifer Miller, University of Florida, USA</p>	

Sunday 17th November

08.00 – 08.30	Registration		
08.45 – 10.00 Lectures then Workshop	<p>Chair: Marguerite Hughes, Vice-President of IPWSO, Ireland</p> <p><i>Is it behaviour or a mental health problem?</i> Tony Holland, University of Cambridge, UK Janice Forster, Pittsburgh Partnership, USA</p>		
10.00 – 10.30	Break		
10.30 – 11.00	<p>Chair: Marilyn Dumont-Driscoll, Board member of IPWSO, USA</p> <p><i>Developing psychological support strategies to help people with PWS deal with change</i> Kate Woodcock, University of Birmingham, UK</p>		
10.30 – 12.00 Lectures then Workshop	<p><i>Room 1 Theatre - Children 0 to 16yrs</i></p> <p>Chair: Marilyn Dumont-Driscoll, Board member of IPWSO, USA</p> <p><i>Early education and school years</i> Elizabeth Roof, Vanderbilt University, USA</p>	<p><i>Room 2 Martí – Adolescents to Adults</i></p> <p>Chair: James O’Brien, Board member of IPWSO, Australia</p> <p><i>Adulthood – work/day program/residential</i> Hubert Soyer, Regens Wagner Absberg, Germany</p>	
12.00 – 12.30	<p>Chair: Marilyn Dumont-Driscoll, Board member of IPWSO, USA</p> <p><i>About IPWSO Country Organisations - getting started</i> Amalia Balart, Board member of IPWSO, Chile</p>		
12.30 – 13.30	Lunch		
13.30 – 14.00	<p>Chair: Tony Holland, President of IPWSO</p> <p><i>Sensory Integration</i> Janice Forster, Pittsburgh Partnership, USA</p>		
14.00 – 14.30	<p><i>Testimonials: If you are not here...?</i> Maria Elvira Garcia, Author of The Thief of Smiles and President of the Colombian PWS Association</p>		
14.30 – 15.00	Break		
15.00 – 15.45 Lectures and open discussion	<p><i>Emotional Development – Room 1 Theatre</i></p> <p>Chair: Georgina Loughnan, Board member of IPWSO, Australia</p> <p>Speaker: Elizabeth Roof, Vanderbilt University, USA</p>	<p><i>Social Interaction – Room 2 Martí</i></p> <p>Chair: James O’Brien, Board member of IPWSO, Australia</p> <p>Speaker: Norbert Hödebeck-Stuntebeck, Diakonische Stiftung Wittekindshof, Germany</p>	<p><i>Friendship, Relationships and Sexuality – Room 3 Bolivar Martí</i></p> <p>Chair: Amalia Balart, Board member of IPWSO, Chile</p> <p>Speaker: Verena Gutmann, Educational Head of Department, Austria</p>
15.45 – 16.15	<p>Questions and Answers from the box and the floor</p> <p>Chair: Amalia Balart with a panel of speakers</p>		

16.15 – 16.30

Close of Conference

Chair: Amalia Balart, Conference chair and Board member of IPWSO, Chile

Speakers: Tony Holland, President of IPWSO and Loisel Bello, Representative of Cuban families with PWS