

# IPWSO's 10<sup>th</sup> International Conference, Havana, Cuba Clinical and Scientific programme: 14<sup>th</sup> to 15<sup>th</sup> November 2019

The conference will be held in the Theatre

Thursday 14<sup>th</sup> November

08.00 – 08.30	Registration
<b>08.30 – 08.45</b>	<b>Introductions</b>
	<b>Chair:</b> Daniel J. Driscoll, University of Florida College of Medicine <b>Co-Chair:</b> Estela Morales Peralta, Medical University of Havana
08.45 – 10.00	<b>I. Genetics, Epigenetics &amp; Animal Models</b> Moderator: Suzanne Cassidy, University of California, San Francisco
08.45 – 09.30	<b>I-1.</b> Invited Talk: <i>“Genetics in PWS: Where We Have Been and Where We are Going”</i> Daniel J. Driscoll, University of Florida College of Medicine
09.30 – 10.00	<b>I-2.</b> Invited Talk: <i>“An Update on Mouse Models of PWS”</i> Jim Resnick, University of Florida College of Medicine The Zafgen lecture
10.00 – 10.30	Break
<b>10.30 – 12.00</b>	<b>II. Endocrinology</b> Moderator: Urs Eiholzer, Center for Pediatric Endocrinology Zurich
10.30 – 11.00	<b>II-1.</b> Invited Talk: <i>“Oxytocin in Prader-Willi Syndrome”</i> Maïthé Tauber, Université Paul Sabatier Toulouse 3 and Hôpital des enfants CHU
11.00 – 11.30	<b>II-2.</b> Invited Talk: <i>“An Overview of Endocrinology in Adults with PWS”</i> Charlotte Höybye, Karolinska University Hospital and Karolinska Institute The Levo Therapeutics lecture
11.30 – 11.45	<b>II-3.</b> <i>“Central adrenal insufficiency is rare in adults with Prader-Willi syndrome”</i> Anna Rosenberg, Erasmus University Medical Center
11.45 – 12.00	<b>II-4.</b> <i>“Systemic Inflammation and The Effect of a GLP-1 Receptor Agonist in Adults with Prader-Willi Syndrome”</i> Jarron Dodds, Garvan Institute of Medical Research and University of Notre Dame
12.00 – 13.00	Lunch and poster viewing
<b>13.00 – 14.30</b>	<b>III. Gastrointestinal &amp; Nutrition</b> Moderator: Maïthé Tauber, Université Paul Sabatier Toulouse 3 and Hôpital des enfants CHU
13.00 – 13.30	<b>III-1.</b> Invited Talk: <i>“Comprehensive Overview of Digestive Issues in Prader-Willi Syndrome”</i> Ann Scheimann, Johns Hopkins School of Medicine
13.30 – 13.45	<b>III-2.</b> <i>“Review of Short and Long-Term Outcomes of Bariatric Procedures in Prader-Willi Syndrome and Other Hyperphagic Disorders”</i> Ann Scheimann, Johns Hopkins School of Medicine
13.45 – 14.00	<b>III-3.</b> <i>“Long-acting GLP-1 agonist treatment in Prader-Willi Syndrome: Benefits on appetite, behaviour and cognition versus risks?”</i> Amanda Hor, Garvan Institute of Medical Research, St Vincent's Hospital and University of New South Wales
14.00 – 14.15	<b>III-4.</b> <i>“Effect of macronutrient composition on postprandial metabolism in children with Prader-Willi syndrome (PWS): preliminary findings”</i> Maha Alsaif, University of Alberta
14.15 – 14.30	<b>III-5.</b> <i>“Relationship between Angiopoietin-like levels and non-alcoholic fatty liver disease in children with Prader-Willi Syndrome”</i> Antonio Crinò, Bambino Gesù Children's Hospital, Research Institute, Palidoro (Rome)
14.30 – 15.00	Break
<b>15.00 – 17.00</b>	<b>IV. General Medical Issues</b> Moderator: Charlotte Höybye, Karolinska University Hospital and Karolinska

	Institute
15.00 - 15.30	<b>IV-1.</b> Invited Talk: <i>“Overview and Evaluation: Infants, Children, Adolescents and Adults with PWS”</i> Susanne Blichfeldt, The Danish Prader Willi Association and Centre for Rare Diseases
15.30 – 16.00	<b>IV-2.</b> Invited Talk: <i>“Medical care for Patients with PWS at the National Network of Medical Genetic Services in Cuba”</i> Estela Morales Peralta, Medical University of Havana
16.00 – 16.15	<b>IV-3.</b> <i>“Incidence and Consequence of Laryngomalacia in Infants with PWS seen at Seattle Children’s PWS Clinic”</i> Parisa Salehi, Seattle Children’s Hospital, University of Washington
16.15 – 16.30	<b>IV-4.</b> <i>“Increased bone density without changes in bone markers in youth with and without PWS who participated in a 24-week physical activity intervention”</i> Daniela Rubin, California State University, Fullerton
16.30 – 16.45	<b>IV-5.</b> <i>“Is There a ‘Fetal Phenotype’ of Prader-Willi Syndrome?”</i> Jude P. Crino, University of Maryland School of Medicine
16.45 – 17.00	<b>IV-6.</b> <i>“Challenges in medical management of obesity hypoventilation in Prader-Willi syndrome”</i> Linda Gourash, Pittsburgh Partnership
<b>17.00 – 18.00</b>	<b>Poster presentations, session #1</b>

## Friday 15<sup>th</sup> November

08.00 – 08.30	Registration
<b>08.30 – 10.00</b>	<b>V. General Medical Issues including Orthopaedics</b> Moderator: Ann Scheimann, Johns Hopkins School of Medicine
08.30 – 09.00	<b>V-1.</b> Invited Talk: <i>“The Orthopaedics of Prader-Willi Syndrome”</i> Harold J. P. van Bosse, Shriners Hospital for Children
09.00 – 09.15	<b>V-2.</b> <i>“Role of Body Cast Application for Scoliosis Associated with Prader-Willi Syndrome”</i> Harold J. P. van Bosse, Shriners Hospital for Children
09.15 – 09.30	<b>V-3.</b> <i>“High prevalence of scoliosis in a large cohort of patients with Prader-Willi syndrome”</i> Antonino Crinò, Bambino Gesù Children’s Hospital, Research Institute, Palidoro (Rome)
09.30 – 09.45	<b>V-4.</b> <i>“Comparative Comorbidity Burden Among Patients With Prader-Willi Syndrome: A Population-Level Cohort Study”</i> Diane Stafford, Stanford University
09.45 – 10.00	<b>V-5.</b> <i>“US prevalence &amp; mortality of Prader-Willi syndrome: A population-based study of medical claims”</i> Shawn E. McCandless, University of Colorado
10.00 – 10.30	Break
<b>10.30 – 12.00</b>	<b>VI. Clinical Trials for Hyperphagia and Behaviour</b> Moderator: Tony Holland, University of Cambridge
10.30 – 11.15	<b>VI-1.</b> Invited Talk: <i>“An Overview of Clinical Trials”</i> Nathalie Kayadjanian, PWS Clinical Trial Consortium
11.15 – 11.30	<b>VI-2.</b> <i>“Tesomet - a new treatment opportunity in Prader Willi Syndrome. Results from Phase 2a exploratory studies in adult and adolescent patients”</i> Dóra Török, Semmelweis University
11.30 – 11.45	<b>VI-3.</b> <i>“Trial-in-Progress: ZEPHYR, a Pivotal Phase 2b/3 Randomized, Placebo-Controlled Study of Livoletide, a Novel Unacylated Ghrelin Analogue, for the Treatment of Hyperphagia and Food-Related Behaviors in Patients With Prader-Willi Syndrome”</i> Vivian H. Lin, MD, Millendo Therapeutics, Inc.
11.45 – 12.00	<b>VI-4.</b> <i>“Effect of topiramate on eating behaviours in Prader-Willi syndrome”</i> Sophie Çabal-Berthoumieu, Centre de Référence du Syndrome de Prader-Willi and Hôpital des Enfants, Toulouse
12.00 – 13.00	Lunch and poster viewing
<b>13.00 – 14.30</b>	<b>VII. Mental Health, Behaviour &amp; Cognition #1</b> Moderator: Susanne Blichfeldt, The Danish Prader Willi Association and Centre for Rare Diseases
13.00 – 13.30	<b>VII-1.</b> Invited Talk: <i>“Mental Health and Behavior in PWS”</i> Janice L. Forster, Pittsburgh Partnership
13.30 – 13.45	<b>VII-2.</b> <i>“Cognitive functioning in children with Prader-Willi syndrome during 8 years of growth hormone treatment”</i> Anita Hokken-Koelega, Dutch Growth Research Foundation and Erasmus University Medical Centre/Sophia Children’s Hospital
13.45 – 14.00	<b>VII-3.</b> <i>“A Genotype-Phenotype Analysis of the Effects of Growth Hormone Treatment on Psychiatric Behavior in Prader-Willi Syndrome”</i> June-Anne Gold, University of California, Irvine
14.00 – 14.15	<b>VII-4.</b> <i>“Gray matter microstructural alteration of the brain in individuals with Prader-Willi syndrome: a 7T MRI study”</i> Kenichi Yamada, University of Niigata
14.15 – 14.30	<b>VII-5.</b> <i>“Bilingualism and Executive Control: the PWS population on the spotlight and... doing well”</i> Estela García-Alcaraz, University of Ottawa and Juana Muñoz-Liceras, University of Ottawa and Universidad Nebrija, Madrid
14.30 – 15.00	Break
<b>15.00 – 16.00</b>	<b>VIII. Mental Health, Behaviour &amp; Cognition #2</b> Moderator: Janice L. Forster, Pittsburgh Partnership

15.00 – 15.15	<b>VIII-1.</b> <i>“Flexible scheduling to prevent the development of disabling resistance to change: acceptability and feasibility of a digital intervention co-produced with stakeholders”</i> Siobhan Blackwell, University of Birmingham
15.15 – 15.30	<b>VIII-2.</b> <i>“A randomised control trial to evaluate the impact of engagement with a task switching training computer game on people with Prader-Willi syndrome”</i> Kate Woodcock, University of Birmingham
15.30 – 15.45	<b>VIII-3.</b> <i>“Specific features in the expression of emotions in children with Prader-Willi syndrome : What are the consequences for emotion abilities and social adjustment?”</i> Nawelle Famelart, University of Toulouse
15.45 – 16.00	<b>VIII-4.</b> <i>“PRACOM 2 project: Study of the emotional aspects associated to behavioral and cognitive troubles in the Prader-Willi Syndrome”</i> Anna-Malika Camblats, Université de Bordeaux
<b>16.00 – 18.00</b>	<b>Poster presentations, session #2</b>