

2025 International PWS Conference Clinical and Scientific Program Agenda



DAY ONE | Wednesday, June 25, 2025

6:30 AM	Breakfast - Food Trucks <i>Conference Center Pavilion; Breakfast not included with conference registration</i>
7:00 AM - 6:00 PM	Conference Check-In / Help Desk Hours <i>Conference Center Lobby (first floor)</i>
8:30 AM - 8:45 AM	Introduction & Welcome (Main Ballroom - Ironwood Doors Entrance) Dan Driscoll, Chair, Clinical and Scientific Advisory Board, IPWSO & Theresa Strong, Director of Research Programs, Foundation for Prader-Willi Research, USA
8:45 AM - 10:15 AM	I. Opening Session Day 1 (Main Ballroom - Ironwood Doors Entrance) Moderator: Theresa Strong, Foundation for Prader-Willi Research, USA
8:45 AM - 9:30 AM	I-1. Invited Speaker: Obesity, Causes and Treatment: The End of the Beginning - Jeffrey M Friedman, Howard Hughes Medical Institute, USA
9:30 AM - 10:15 AM	I-2. Invited Speaker: Epigenetic Activation of the PWS Locus as a Potential Therapeutic Approach - Marnie Blewitt, The Walter and Eliza Hall Institute of Medical Research and Department of Medical Biology, University of Melbourne, Australia
10:15 AM - 10:45 AM	BREAK
10:45 AM - 11:45 AM	II. Genetics & Epigenetics (Main Ballroom - Ironwood Doors Entrance) Moderator: Jim Resnick, University of Florida, College of Medicine, USA
10:45 AM - 11:00 AM	II-1. Convergence of Transcriptional and Molecular Signatures in Prader-Willi Syndrome - Derek JC Tai, Center for Genomic Medicine, Massachusetts General Hospital, Harvard Medical School, USA
11:00 AM - 11:15 AM	II-2. Changes in the Transcriptomic Landscape of the Hypothalamus in Prader-Willi Syndrome - Gina Yosten, St Louis University School of Medicine, USA
11:15 AM - 11:30 AM	II-3. Gene Dysregulation in Isogenic Models of Prader-Willi Syndrome - Gordon Carmichael, University of Connecticut Health Center, USA
11:30 AM - 11:45 AM	II-4. Transcription Profiling of SNORD109 and SNORD116 in the Human Hypothalamus and Cerebellum identifies Novel Human-Specific Expression Patterns - Lara Lechner, Charité, Universitätsmedizin Berlin, Germany
11:45 AM - 12:45 PM	Networking Lunch <i>Canyon Ballroom</i>
12:45 PM - 1:45 PM	III. Medical (Main Ballroom - Ironwood Doors Entrance) Moderator: Ann Scheimann, Johns Hopkins Hospital, USA
12:45 PM - 1:00 PM	III-1. Is there a role for GLP-1 Receptor Agonists in Prader-Willi Syndrome? - Ann Manzardo, University of Kansas Medical Center, USA
1:00 PM - 1:15 PM	III-2. Efficacy and Tolerance of SGLT2 Inhibitors in Diabetic Patients with Prader-Willi Syndrome: Non-Insulin Diabetes Treatment - Christine Poitou, Service de diabétoogie et nutrition, Hôpital Pitié-Salpêtrière, Centre de Référence Pradort, France
1:15 PM - 1:30 PM	III-3. An AI Program to Determine the Nutritional Phase of PWS - Dan Driscoll, University of Florida College of Medicine, USA
1:30 PM - 1:45 PM	III-4. The Clinical Presentation of Prader-Willi in the Inpatient and Emergency Settings: Insights from Real-World Evidence - James Luccarelli, Massachusetts General Hospital and Harvard Medical School, USA
1:45 PM - 1:55 PM	BREAK

1:55 PM - 2:40 PM	IV. Oral/Poster Lightning Talks Session 1 (<i>Main Ballroom - Ironwood Doors Entrance</i>) Moderator: Dan Driscoll, University of Florida College of Medicine, USA
1:55 PM - 2:00 PM	IV-1. Functional Near-Infrared Spectroscopy of Skin Picking Behavior in Prader-Willi Syndrome - Scott Hall, Stanford University School of Medicine, USA
2:00 PM - 2:05 PM	IV-2. The Heart of SNORD116: Investigating the Role of SNORD116 in Cardiomyocyte Development - James Smith, University of East Anglia, United Kingdom
2:05 PM - 2:10 PM	IV-3. Reduction in Hyperphagia in ARD-101 Phase 2 Clinical Trial Informs Phase 3 HERO Trial in PWS - Manasi Jaiman, Aardvark Therapeutics, USA
2:10 PM - 2:15 PM	IV-4. Assessing Osteoarticular Challenges in Prader-Willi Syndrome: Insights into postural stability, spinal deformities, and functional mobility - Jorgelina Stegmann, Fundación Spine, Argentina
2:15 PM - 2:20 PM	IV-5. N-Acetylcysteine Treatment for Skin-Picking in Children and Young Adults with PWS: A randomized placebo-controlled cross-over trial - Demi Trueba-Timmermans, Erasmus MC Sophia, The Netherlands
2:20 PM - 2:25 PM	IV-6. Circulating Levels of Ghrelin in Patients with a Rare Neurodevelopmental Disorder Associated with Hyperphagia, and/or Overweight, and/or Obesity – The HOGGRID study - Gwenaëlle Diene, CHU de Toulouse, France
2:25 PM - 2:30 PM	IV-7. The Burden of Anxiousness and Distress Behaviors in Prader-Willi Syndrome - Deborah Hoffman, Acadia Pharmaceuticals Inc, USA
2:30 PM - 2:35 PM	IV-8. Mining Biological Networks at Scale: A Path to New Therapeutic Targets in Prader-Willi Syndrome - Rohit Singh, Duke University, USA
2:35 PM - 2:40 PM	IV-9. Study Design and Ethical Return of Results for a Fully Remote Genome Sequencing Study in Individuals with Prader-Willi Syndrome - Caroline Vrana-Diaz, Foundation for Prader-Willi Research, USA
2:40 PM - 3:00 PM	BREAK
3:00 PM - 4:00 PM	V. Oral/Poster Lightning Talks Session 2 (<i>Main Ballroom - Ironwood Doors Entrance</i>) Moderator: Theresa Strong, Foundation for Prader-Willi Research, USA
3:00 PM - 3:05 PM	V-1. Delivery of Genes and Gene Editors using Programmable Milk Exosomes - Janos Zemleni, University of Nebraska-Lincoln, USA
3:05 PM - 3:10 PM	V-2. Learning from People Living with PWS Across the World About How to Best Support their Flourishing - Kate Woodcock, University of Birmingham, United Kingdom
3:10 PM - 3:15 PM	V-3. Role of Mitochondrial Function in the Oxidative Stress Profile of Children with Prader-Willi Syndrome - Alvaro Carrasco-Garcia, Erasmus University Medical Center, The Netherlands
3:15 PM - 3:20 PM	V-4. Novel Insights into the Function of MAGEL2 in Fed and Fasted States - Klementina Fon Tacer, Texas Tech University, School of Veterinary Medicine, USA
3:20 PM - 3:25 PM	V-5. Sensory Information Processing, Intelligence, and Behavior in Prader-Willi Syndrome - Anja Roubos, Centre of Excellence for Neuropsychiatry, Vincent Van Gogh, Institute for Psychiatry, The Netherlands
3:25 PM - 3:30 PM	V-6. Long-Term Outcomes of Prader-Willi Syndrome Association USA Funding Awards - Ann Scheimann, Johns Hopkins Hospital, USA
3:30 PM - 3:35 PM	V-7. The Dutch experience with Weight-Loss Drugs in Adults with Prader-Willi Syndrome - Jacqueline Goos, Erasmus MC University Medical Center, The Netherlands
3:35 PM - 3:40 PM	V-8. Respiratory and Sleep Disorders in Children with Prader Willi Syndrome: prevalence and characterization - Sofia Suco, Hospital de Niños icardo Gutierrez - Cedio, Buenos Aires, Argentina
3:40 PM - 3:45 PM	V-9. Eating behavior and Hyperphagia in Adults with Obesity and Neurodevelopmental Disorders: Insights from Prader-Willi, Bardet-Biedl and other genetic syndromes - Emilie Guillon, Pitié-Salpêtrière Hospital, France
3:45 PM - 3:50 PM	V-10. Hypercapnia is Common in Lean and Obese Adults with Prader Willi Syndrome - Kristen Davidse, Erasmus University Medical Centre, The Netherlands
3:50 PM - 3:55 PM	V-11. International Survey of Clinicians' Perspectives Toward Growth Hormone Therapy and Sleep Evaluation in Infants with Prader-Willi Syndrome - Emily Paprocki, Children's Mercy Kansas City, USA
4:00 PM - 6:00 PM	VI. Poster Presentation Session (<i>Arizona E, H - Eucalyptus & Honeysuckle - Honeysuckle Door Entrance</i>) Light refreshments will be served.

2025 International PWS Conference Clinical and Scientific Program Agenda



DAY TWO | Thursday, June 26, 2025

6:30 AM	Breakfast - Food Trucks <i>Conference Center Pavilion; Breakfast not included with conference registration</i>
7:00 AM - 8:00 PM	Conference Check-In / Help Desk Hours <i>Conference Center Lobby (first floor)</i>
8:15 AM - 10:00 AM	VII. Opening Session Day 2 (Main Ballroom - Ironwood Doors Entrance) Neuroscience, Cognition, and Mental Health Moderator: Janice Forster, Pittsburg Partnership, USA
8:15 AM - 9:00 AM	VII-1. Invited Speaker: Maintaining Well-Being, Improving Mental Health, and Managing Challenging Behaviors: Outcomes from the IPWSO Mental Health Initiative - Anthony J Holland, Professor Emeritus, University of Cambridge, United Kingdom
9:00 AM - 9:15 AM	VII-2. How Oxytocin Acts and Restores the Suckling Behavior in Magel2 Deficient Newborn Mouse: consequences on Prader-Willi and Schaaf-Yang Syndrome - Françoise Muscatelli, Institut de Neurobiologie de la Méditerranée, France
9:15 AM - 9:30 AM	VII-3. Morphological and Transcriptional Alterations of Microglia in the Magel2 KO Mouse Model of Prader-Willi Syndrome - Ferdinand Althammer, Institute of Human Genetics, Heidelberg University Hospital, Germany
9:30 AM - 9:45 AM	VII-4. Physiological, Behavioral, and Neurodevelopmental Consequences of the Combined Loss of Necdin and Magel2 - Sebastien Bouret, INSERM UMR-S 1172 Lille Neuroendocrinology, France
9:45 AM - 10:00 AM	VII-5. Investigating Mechanisms of Psychosis in Prader-Willi Syndrome using Magnetic Resonance Spectroscopy - Suzannah Lester, University of Cambridge, United Kingdom
10:00 AM - 10:15 AM	BREAK
10:15 AM - 11:00 AM	VIII. Moderator: Charlotte Höybye, Karolinska Institute, Sweden (Main Ballroom - Ironwood Doors Entrance) Invited Speaker: Mapping Brain Circuitry Involved in Hyperphagia in Prader-Willi syndrome to Identify Novel Treatment Targets - Laura Holsen, Associate Professor of Psychiatry, Harvard Medical School, USA
11:00 AM - 12:00 PM	IX. Clinical / Clinical Trials (Main Ballroom - Ironwood Doors Entrance) Moderator: Charlotte Höybye, Karolinska Institute, Sweden
11:00 AM - 11:15 AM	IX-1. Long-term Efficacy Results of Diazoxide Choline Extended-Release (DCCR) Tablets in Participants with Prader-Willi Syndrome from the Completed C601 (DESTINY PWS) and C602 Open Label Extension (OLE) Studies - Evelien Gevers, Queen Mary University of London, Barts and the London Medical School, United Kingdom
11:15 AM - 11:30 AM	IX-2. A Randomized, Double-Blind, Controlled Trial of Bright Light Therapy on All-Cause Excessive Daytime Sleepiness in Prader-Willi Syndrome - Hasan Mustafic, Maimonides Medical Center, USA
11:30 AM - 11:45 AM	IX-3. My Hunger Questionnaire (My-HQ): Progress in Developing a Self-Report Measure of Hyperphagia for Individuals with Prader-Willi Syndrome - Elisabeth Dykens, Vanderbilt University, USA
11:45 AM - 12:00 PM	IX-4. The James Henson PWS Goal Inventory: An Adaptation of Goal Attainment Scaling for Prader-Willi Syndrome - Maria Picone, TREND Community, USA
12:00 PM - 1:00 PM	Networking Lunch <i>Canyon Ballroom</i>
1:00 PM - 2:30 PM	X. Clinical Care (Concurrent Session) (Main Ballroom - Ironwood Doors Entrance) Moderator: Constanze Lämmer, Section of Paediatric Endocrinology and Diabetology, Dept. of Paediatrics and Adolescent Medicine, KJF Klinikum Josefinum, Augsburg, Germany
1:00 PM - 1:15 PM	X-1. Serious Medical Events and PWS-associated behaviors in PATH for PWS: A Non-Interventional, Observational, Natural History Study of Prader-Willi Syndrome - Lisa Matesevac, Foundation for Prader-Willi Research, USA

1:15 PM - 1:30 PM	X-2. Utility of Baseline Polysomnograms Prior to Growth Hormone Initiation in Young Infants with PWS - Sani Roy, Cook Children's Medical Center, USA
1:30 PM - 1:45 PM	X-3. The Effects of Growth Hormone Treatment on Muscle Strength in Adults with Prader-Willi Syndrome - Jannek Baan, Erasmus Medical Centre, The Netherlands
1:45 PM - 2:00 PM	X-4. Testosterone Replacement Therapy in Adolescents and Young Adults with Prader-Willi Syndrome: Efficacy and Effects on Behavior - Gerthe Kerhof, Dutch Reference Centre for PWS, The Netherlands
2:00 PM - 2:15 PM	X-5. Developmental Characterization of Phenotypic Behaviors in PWS - Janice Forster, Pittsburgh Partnership, USA
2:15 PM - 2:30 PM	X-6. The Lived Experiences of Teens and Adults Who Grew Up with a Sibling with Prader-Willi Syndrome - Lauren Schwartz, Foundation for Prader-Willi Research, USA
1:00 PM - 2:30 PM	XI. Molecular (Concurrent Session) (Acacia) Moderator: Jim Resnick, University of Florida, College of Medicine, USA
1:00 PM - 1:15 PM	XI-1. Light and Sex Modify Snord116 Genotype Effects on Metabolism, Behavior, and Imprinted Gene Networks following Circadian Entrainment - Estefania Azevedo, MUSC, USA
1:15 PM - 1:30 PM	XI-2. In Silico Drug Repurposing Using Human Brain Omics Data Reveals Targetable Pathways for Prader-Willi Syndrome - Olivia Veatch, University of Kansas Medical Center, USA
1:30 PM - 1:45 PM	XI-3. A Cholinergic Hypothesis Driving Hyperphagia and Cognitive Deficits in Prader-Willi Syndrome - Estefania Azevedo, MUSC, USA
1:45 PM - 2:00 PM	XI-4. The Similarities between Congenital Myasthenic Syndrome-22 and Prader-Willi Syndrome: Activating the PREPL Pathway as a Potential Therapeutic Approach for PWS - Yenthe Monnens, KU Leuven, Belgium
2:00 PM - 2:15 PM	XI-5. Does SNORD116 Play a Role in Ribosome Biogenesis? - Amanda Whipple, Harvard University, USA
2:15 PM - 2:30 PM	XI-6. An innovative delivery of CRISPR/dCas9 epigenome editing-based therapy for Prader-Willi Syndrome - Xiaona Lu, Yale University School of Medicine, USA
2:30 PM - 3:00 PM	Break and Poster Viewing <i>Main Ballroom and Arizona E, H - Eucalyptus & Honeysuckle</i>
3:00 PM - 4:00 PM	XII. Closing Session (Main Ballroom - Ironwood Doors Entrance) Moderator: Tony Holland, University of Cambridge, UK
3:00 PM - 3:15 PM	XII-1. Hypothalamic-Related Neural Activity at Rest in Prader-Willi Syndrome - Sanaz Hosseini, University of Cambridge, United Kingdom
3:15 PM - 3:30 PM	XII-2. Oxytocin System Dysregulation is a Key Feature in Magel2 Pmut Rats and Associated with Changes in Protein Secretion Pathways - Tim Schubert, Institute of Human Genetics, Heidelberg University, Germany
3:30 PM - 3:45 PM	XII-3. High Throughput Screening to Identify Drugs that Ameliorate Secretory Granule Phenotypes in PWS iPSC-Derived Neurons - Anne Bang, Sanford Burnham Prbys Medical Discovery Institute, USA
3:45 PM - 4:00 PM	XII-4. Current Psychopharmacological Prescribing Practices in Prader-Willi Syndrome - Findings from the PATH for PWS Study - Deepan Singh, Maimonides Medical Center, USA
4:00 PM - 4:30 PM	XIII. Close (Main Ballroom - Ironwood Doors Entrance)
4:00 PM - 4:15 PM	XIII-1. Outstanding Young Investigator Presentation Chair: Ann Scheimann, Clinical and Scientific Advisory Board, PWSA USA
4:15 PM - 4:30 PM	XIII-2. Final Comments