

IPWSO 2022 - 11th International Conference, Limerick, Ireland

Clinical and Scientific programme: 7 to 8 July 2022

Thursday 7 July

08.00 – 08.30	Registration
08.30 – 08.45	Introductions
	Chair: Daniel J. Driscoll, University of Florida College of Medicine, USA
08.45 – 09.45	I. Opening Session Moderator: Daniel J. Driscoll, University of Florida College of Medicine, USA
08.45-09.00	I-1. Introductory Talk: A message to the scientists from a parent of a person with PWS Deborah Barks, Remetschwil, SWITZERLAND
09.00-09.45	I-2. Invited Talk: Neuroplacentology in PWS: implications for our understanding of early phenotypes Miguel Constanca, School of Clinical Medicine, University of Cambridge, UK
09.45–10.15	Break
10.15 – 12.00	II. Genetics and Epigenetics Moderator: Anthony Holland, University of Cambridge, UK
10.15 – 11.00	II-1. Invited Talk: Insights into Prader-Willi syndrome through investigation of the human hypothalamus Elena Bochukova, Queen Mary University of London, UK
11.00 – 11.15	II-2. Dysregulation of RBFOX1 Protein May Be Responsible for Many of the Clinical Features of PWS Daniel J. Driscoll, University of Florida College of Medicine, USA
11.15 – 11.30	II-3. Long-read whole genome sequencing reveals novel common genetic variants in Prader-Willi syndrome Maximilian Deest, Hannover Medical School, GERMANY
11.30 – 11.45	II-4. Investigating ZNF274-mediated repression of maternal 15q11-q13 Rachel B. Gilmore, University of Connecticut Health Centre, USA
11.45 – 12.00	II-5. Hyperphagia-related behavior and epigenetic alterations of appetite-regulating hormones in Prader-Willi syndrome Jelte Wieting, Hannover Medical School, GERMANY
12.00 – 13.00	Lunch and poster viewing
13.00 – 14.30	III. Endocrinology Moderator: Charlotte Höybye, Karolinska University Hospital and Karolinska Institute, SWEDEN
13.00 – 13.15	III-1. Long-term growth hormone treatment in young children with PWS: The earlier the start, the better the outcome? Lionne N. Grootjen, Dutch Reference Center for Prader-Willi Syndrome, THE NETHERLANDS
13.15 – 13.30	III-2. Long-Term Effects of GH Therapy in Adult Patients with Prader-Willi Syndrome: a Longitudinal Study Graziano Grugni, Istituto Auxologico Italiano, ITALY
13.30 – 13.45	III-3. MKRN3 circulating levels in Prader-Willi Syndrome: a pilot study Danilo Fintini, Bambino Gesù Children's Hospital, ITALY
13.45 – 14.00	III-4. The Therapeutic Potential of a Cannabidiolic Acid Derivative for Treating Hyperphagia and Obesity in PWS Joseph Tam, Hebrew University of Jerusalem, ISRAEL
14.00 – 14.15	III-5. Malignancies in Prader-Willi syndrome: practical recommendations based on a large international cohort and review of the literature Karlijan Pellikaan, Erasmus University Medical Center, THE NETHERLANDS
14.15 – 14.30	III-6. The evolution of diagnosis and care over time in children with Prader-Willi syndrome, born between 2005 and 2021, included in the French database Maithé Tauber, Centre de Référence du syndrome de Prader-Willi, Hôpital des Enfants, Toulouse, FRANCE
14.30 – 15.00	Break
15.00 – 17.00	Poster Presentations, Session 1

Friday 8 July

08.00 – 08.30	Registration
08.30 – 10.00	IV. Medical and Gastrointestinal Issues Moderator: Ann Scheimann, Johns Hopkins School of Medicine, USA
08.30 – 08.45	IV-1. Dysphagia: a core symptom of Prader-Willi syndrome Pascale Fichaux-Bourin, Centre de Référence du Syndrome de Prader-Willi. Hôpital des Enfants, Toulouse, FRANCE
08.45 – 09.00	IV-2. Swallowing assessment in people with Prader Willi Syndrome Jorgelina Stegmann, SPINE Foundation, ARGENTINA
09.00 – 09.15	IV-3. Lymphedema in Adults with Prader-Willi Syndrome Melanie Ehard, Institute of General Practice, Friedrich-Alexander University, GERMANY
09.15 – 09.30	IV-4. High Prevalence of Lower Urinary Tract Dysfunction in Patients with Prader-Willi syndrome Li-Ping Tsai, Taipei Tzu Chi Hospital, TAIWAN
09.30 – 09.45	IV-5. PATH for PWS Study 2022 Update: A Non-Interventional, Observational, Natural History Study of Serious Medical Events in Prader-Willi Syndrome Theresa Strong, Foundation for Prader-Willi Research, USA
09.45 – 10.00	IV-6. Reducing Global Health Inequalities for a Rare Disorder: Evaluating the International Prader-Willi Syndrome Organisation's ECHO® Programme Tanzil Rujeedawa, University of Cambridge, UK
10.00 – 10.30	Break
10.30 – 12.00	V. Mental Health, Neuroscience and Behaviour - I Moderator: Leopold Curfs, Maastricht University, THE NETHERLANDS
10.30 – 11.15	V-1. Invited Talk: Using mouse models to understand the molecular bases of psychotic illness in PWS Anthony R. Isles, Cardiff University, UK
11.15 – 11.30	V-2. Model for Behavioral Caregiver Training for Prader-Willi Syndrome Kasey Bedard, The Chicago School of Professional Psychology, USA
11.30 – 11.45	V-3. The Feasibility and Effectiveness of a Novel, On-line Social Skills Intervention for Individuals with Prader-Willi Syndrome Elisabeth M Dykens, Vanderbilt University, USA
11.45 – 12.00	V-4. Evaluating Skin Picking in Prader Willi syndrome Jorgelina Stegmann, SPINE Foundation, ARGENTINA
12.00 – 13.00	Lunch and poster viewing
13.00 – 14.30	VI. Mental Health, Neuroscience and Behaviour - II Moderator: Janice L. Forster, Pittsburgh Partnership, USA
13.00 – 13.45	VI-1. Invited Talk: PWS - a model for understanding the wiring of the social brain Freddy Jeanneteau, University of Montpellier, FRANCE
13.45 – 14.00	VI-2. The Food Attentional Bias (FAB) Task - An eye-tracking paradigm to measure satiety Sarah Feighan, Trinity College Dublin, IRELAND
14.00 – 14.15	VI-3. Neuroimaging Evidence For Impaired Hypothalamic Development in Prader-Willi Syndrome Stephanie S. G. Brown, University of Cambridge, UK
14.15 – 14.30	VI-4. The Prader-Willi Syndrome Anxiousness and Distress Behaviors Questionnaire (PADQ): Initial Psychometric Evaluation in the Global PWS Registry Cohort Lauren Schwartz. Foundation for Prader-Willi Research, USA
14:30-15:00	Break

15.00 – 15.45	VII. Clinical Trials Moderator: Maithé Tauber, University of Toulouse, FRANCE
15.00 – 15.15	VII-1. Long-Term Safety of Diazoxide Choline Extended-Release (DCCR) Tablets in Patients with Prader-Willi Syndrome Jennifer L. Miller, University of Florida, USA
15.15 – 15.30	VII-2. Application of a novel hybrid natural language processing-qualitative analytic method to characterize efficacy of DCCR in Prader-Willi syndrome Adam Pittman, Folia Health, USA
15.30 – 15.45	VII-3. The use of focus groups to adapt a protocol for collecting eye-tracking data from people with Prader-Willi Syndrome Áine McNicholas, Trinity College, IRELAND
15:45 – 16:00	Concluding Remarks Daniel J. Driscoll, University of Florida College of Medicine, USA
16.00 – 18.00	Poster Presentations, Session 2

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