# **International PWS Meeting 2022**

### Programme Friday 20 May 2022

12:00-12:30 Registration and lunch 12:30 - 12:40 Welcome and introduction of INfoRMEd-PWS network Laura de Graaff (Scientific Programme Chair) Christine Poitou (Basic Science Joint Chair) Tony Goldstone (Basic Science Joint Chair) Graziano Grugni (Clinical Science Joint Chair) Assumpta Caixás (Clinical Science Joint Chair) Charlotte Höybye (Clinical Science Joint Chair)

#### 12:40-14:10 Session 1: PWS - The Basics

12:40-13:00 Basic knowledge about PWS, the role of the hypothalamus **Tony Goldstone** *(UK)* 

13:00-13:20 'Classical' vs 'next generation' PWS: what are the differences, what does this mean for the clinic? **Graziano Grugni** *(Italy)* 

13:20-13:40 PWS across the life span. What is known from historical research data? **Charlotte Höybye (Sweden)** 

13:40- 14:10 Genetics of PWS Jessica Bohonowych (USA)

14:10 - 14:40 Coffee break

### 14:40-15:40 Session 2: A practical approach to PWS

14:40-15:00 The unmet needs of adults with PWS: what should a multidisciplinary team look like? Assumpta Caixás (Spain)

15:00-15:20 Benefits of residential specialist homes, supported living. **Tony Goldstone** *(UK)* 

15:40-16:00 Pitfalls in clinical care for adults with PWS. Effect (detection and treatment of) pituitary hormone deficiencies on physical activity and obesity Laura de Graaff (*Netherlands*)

#### 15:40-16:10 Coffee break

## 16:10-18:30 Session 3: Special challenges in healthcare for patients with PWS

16:10-16:40 Transition of care from paediatric to adult endocrinology **Kirsten Davidse (The Netherlands)** 

16:40-17:10 Obesity-Related Cardiopulmonary Crisis in Prader-Willi Syndrome: Recognition, Management and Prevention Linda Gourash (USA) REMOTE SPEAKER

17:10-17:40 Interpretation of laboratory data and cardiovascular imaging in patients with (severe) obesity **Judith Cuypers (Netherlands)** 

17:40-18:10 Behavioural aspects, caregiver burden and stress, caregiver training education program, coping strategies **Norbert Hodebecke-Stuntebeck** (*Netherlands*)

18:10-18:30 Radius Health: Synthetic cannabidiol -Hyperphagia associated with PWS – clinical development.

18:30-19:00 Drinks reception at MiCo 19:00 onwards - Off-site dinner

### Programme Saturday 21 May 2022

## 09:00-10:30 Session 4: Challenges in endocrine care for adults with PWS

09:00-09:15 The hypothalamus-pituitary-adrenal axis in PWS: diagnosis and management **Anna Rosenberg (The Netherlands)** 

09:15-09:30 Hypogonadism: Diagnosis and management, behavioural issues (psychosis, interaction with psychopharmacologic medication). Sexuality and Relationships

Laura De Graaff (The Netherlands)

09:30-09:45 Bariatric surgery in PWS Antonino Crinó (Italy)

09:45-10:00 Bone problems in PWS (osteoporosis, scoliosis), what about vitamin D? **Tania Markovic (Australia)** 

10:00-10:15 Diabetes in PWS: is it different? Tania Markovic (Australia) 10:15-10:30 Benefits of GH treatment in adults with PWS (update on GH trials in adults with PWS, The GH /IGF axis, IGF bioactivity in PWS) **Charlotte Höybye (Sweden)** 

10:30-11:00 Coffee break

### 11:00-12:30 Session 5: Hyperphagia and obesity

11:00-11:20 Adipose tissue and insulin sensitivity: why is it different in PWS?

### Christine Poitou-Bernert (France)

11:20-11:40 Physical exercise (how to improve it, impact of GH treatment, impact of physical exercise on obesity and metabolic issues) **Georgina Loughnan** (Australia)

11.40-12:10 An overview of appetite-inhibiting drugs and an update on current trials

Tony Goldstone (UK)

12:10-12:30 DCCR Update Evelien Gevers (UK)

12:30 Meeting close and lunch