

International PWS Meeting 2020 Programme

Friday 22 May 2020

12:00 - 12:30 **Registration and Lunch**

12:30 - 12:40 Welcome and introduction of INfoRMEd-PWS network

Laura de Graff (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 Hoybye (Clinical Science Joint Chair)

12:40 - 13:30 **Session 1: PWS- the basics**

Basic knowledge about PWS, the role of the hypothalamus

‘Classical’ vs ‘next generation’ PWS: what are the differences, what does this mean for the clinic?

PWS across the life span. What is known from historical research data?

13:30 – 15:30 **Session 2: A practical approach to PWS**

The unmet needs of adults with PWS: what are the problems, how can they be addressed? What should a multidisciplinary PWS team look like?

Benefits of residential specialist homes, supported living

A new patient with PWS enters the consulting room. A personalised approach

Pitfalls in clinical care for adults with PWS? Importance of medical screening

Physical exercise (how to improve it, impact of GH treatment, impact of physical exercise on obesity and metabolic issues)

Genetic update on PWS / pending research questions (both patient care and genetics)

15:30 – 16:00 **Coffee break**

16:00 – 17:30 **Session 3: Endocrine healthcare for patients with PWS**

Transition of care from paediatric to adult endocrinology

Medication issues after transition to adulthood

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Stress-related health issues after transition to adulthood

Cardiology and PWS, the role of lipids and hormones

Interpretation of laboratory data and cardiovascular imaging in patients with (severe) obesity

17:30 – 18:00 **Session 4: Neuropsychology of PWS**

Behavioural aspects, caregiver burden and stress, caregiver training education program, coping strategies

18:30

onwards

Evening: offsite dinner for all meeting attendees

Saturday 23 May 2020

08:30 – 10:30 **Session 5: Challenges in endocrine care for adults with PWS**

The hypothalamus-pituitary-adrenal axis in PWS: diagnosis and management

Hypogonadism: Diagnosis and management, behavioural issues (psychosis, interaction with psychopharmacologic medication)
Sexuality and relationships

Thyroid hormone deficiency in PWS adults, the role of T3

Bone problems in PWS (osteoporosis, scoliosis), what about vitamin D?

Diabetes in PWS: is it different?

Benefits of GH treatment in adults with PWS (update on GH trials in adults with PWS, The GH /IGF axis, IGF bioactivity in PWS)

Impact of pituitary hormone replacement therapy on physical activity and obesity

10:30 – 11:00 **Coffee break**

11:00 - 13:00 **Session 4 : Hyperphagia and obesity**

Adipose tissue and insulin sensitivity: why is it different in PWS?

The physiology of appetite

Hyperphagia across the lifespan

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Pica and disgust: why do people with PWS eat inedible things?

An overview of appetite-inhibiting drugs and an update on current trials

Results of the DESTINY study (diazoxide choline)

13:00

Meeting close and lunch