

## International PWS Meeting 2020

A collaboration between INfoRMEd-PWS and the European Society of Endocrinology

The first International Prader Willi Syndrome (PWS) Meeting, organised by INfoRMEd-PWS, will take place on May 22<sup>nd</sup> and 23<sup>rd</sup> prior to the 2020 European Congress of Endocrinology in Prague.

### About INfoRMEd-PWS

INfoRMEd-PWS is the International Network for Research, Management & Education on adults with PWS. It brings together leading PWS experts from The Netherlands, Sweden, Italy, France, Spain, the United Kingdom and Australia. The network is coordinated by Dr Laura de Graaff-Herder.

# INfoRMEd-PWS

International Network for Research, Management & Education  
on adults with PWS

**Dr Assumpta Caixas Pedragos** (adult endocrinologist)  
Hospital de Sabadell, Sabadell, Spain

**Dr. Graziano Grugni** (adult endocrinologist)  
Italian Auxological Institute, Verbania, Italy

**Ass. Prof. Charlotte Hoybye** (adult endocrinologist)  
Karolinska University Hospital, Stockholm, Sweden

**Ass. Prof. Tania Markovic** (adult endocrinologist)  
Royal Prince Alfred Hospital, Camperdown, Australia

**Prof. Christine Poitou-Bernert** (adult endocrinologist)  
Pitié-Salpêtrière Hospital, Paris, France

**Dr. Tony Goldstone** (adult endocrinologist)  
Imperial College, London, United Kingdom

**Dr. Laura de Graaff-Herder** (adult endocrinologist)  
Erasmus University Medical Center, Rotterdam, The Netherlands



### European Society of Endocrinology

Starling House, 1600 Bristol Parkway North, Bristol, BS34 8YU, UK Tel +44 1454 642247 [info@euro-endo.org](mailto:info@euro-endo.org) [www.es-e-hormones.org](http://www.es-e-hormones.org)

The objective of INfoRMEd-PWS is to serve as a forum for communication and collaboration about medical and scientific research advances, medical standards, and new therapies. INfoRMEd-PWS was set up to improve collaboration between adult endocrinologist taking care of adults with PWS in different countries.

**Background of INfoRMEd -PWS:**

Although clinical and investigational activities around children with PWS are well established, this was not the case for adults. Adults have different problems and needs than children with PWS, and this is especially true for adults with classical PWS.

Multidisciplinary care and GH treatment have generated a totally new generation of PWS patients which are leaner, healthier and more actively participating in society. This is in contrast with the classical PWS adults who often have morbid obesity, live a sedentary life in residential homes, have severe behavioural problems, develop multiple secondary complications and eventually die at a young age.

Adults with classical PWS have different medical needs than the new generation of adults with PWS.

However, the available guidelines and best practices are generally based on research data from children and (new generation) young adults. These guidelines and best practices are not helpful for adult endocrinologists taking care of adults with classical PWS. Adult endocrinologist who see adults with PWS in the clinic, should have easy access to expert help and support.

The INfoRMEd-PWS network aims to

- Coordinate research activities involving adults with PWS
- Form a relatively large cohort of adults with PWS to obtain strong research results
- Improve availability of guidelines and best practices aimed at classical PWS
- Make information about adults with PWS easily accessible
- Discuss clinical, societal and strategic issues around adults with PWS

INfoRMEd-PWS activities are to

- Carry out clinical trials regarding new treatments for adults with PWS
- Write projects and grant applications together as funding for rare disorders are limited
- Provide reliable written information about adults with PWS (websites, handbook)
- Collect, analyse and publish clinical data from adult PWS from different countries, which can be helpful in improving patient care
- Improve education about adults with PWS (for medical residents, nurses, professional caregivers)
- De-implement of common practices that are based on research data obtained in children, which are not beneficial for adults with PWS
- Address societal needs of adults with PWS, for example by showing the medical benefits of specialised PWS living facilities for adults with PWS
- Advise pharmaceutical companies about which research strategies should have priority and would be beneficial for adults with PWS
- Advise authorities on administrative and financial strategies involving adults with PWS

**International PWS Meeting 2020.**

This meeting is the first in its kind that would take place in Europe.

After attending this meeting, the attendee will

1. be familiar with the basics of Prader-Willi Syndrome
2. be aware of the complexity and the pitfalls of the syndrome

3. have tools to provide good medical care to adults with PWS
4. know about the most recent developments and new therapies

On top of this, the attendee will

1. know what INfoRMEd-PWS is and how INfoRMEd-PWS can be contacted when expert opinion is needed about adults with PWS
2. have met new colleagues during the meeting

**Attendees:**

The meeting is targeted towards international professionals with special interest in the care of adult patients with Prader Willi Syndrome. Although the focus will be on internal medicine and endocrine matters, it will also be interesting for other disciplines like cardiologists, nutritionists, clinical geneticists, physicians for intellectual disabilities and paediatricians. Paramedical professionals (physiotherapists, dietitians), nurses, psychologists, and professional caregivers are also welcome.

**Contacts**

For INfoRMEd-PWS: Laura de Graaff-Herder, [praderwilli@erasmusmc.nl](mailto:praderwilli@erasmusmc.nl)

For ESE: Dirk De Rijdt, [dirk.de-rijdt@ese-hormones.org](mailto:dirk.de-rijdt@ese-hormones.org)