

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 and Australia. The network is coordinated by Dr Laura de Graaff-Herder.

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

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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

