

Roundtable on gonadal function, puberty, sexuality and fertility in people with PWS hosted by the Clinical and Scientific Advisory Board and the Professional Providers and Caregivers Board of IPWSO on Wednesday 13 November 2019, from 14.00 to 17.00 at the Cojimar Conference Centre.

Many children and adults with PWS have impaired sexual development due to gonadal (testes or ovaries) hypofunction as a consequence of insufficient stimulation from the hypothalamus. Standard treatments are generally available to normalize the levels of sex hormones with the aim of achieving normal puberty, libido and fertility, as well as normalizing sex hormone-dependent metabolic processes. Since about the year 2000, adolescents and adults with PWS have been treated with sex hormones, however, often at significantly subnormal doses. There appears to be a subliminal fear that replacement of the missing sex hormones will provoke aggressive behavior, mood changes, mental disorders or problems as a consequence of developing sexuality.

At this roundtable, as part of an audience discussion, all aspects will be considered as pubertal development is not only about hormonal change but it is also an important social process. We want to share the experience you have had with and without the substitution of sex hormones for people with PWS and how treatment may have influenced mood, behavior and/or sexuality. What are the advantages and disadvantages of the hormones used, the doses prescribed, at which age to start and with which formula? Experience has shown that people with PWS talk about romantic feelings and like cuddling but real sexual intercourse is probably rare – perhaps even less common among men than women with PWS. Sexuality also should not be burdened by a possible pregnancy. That is why this roundtable is also about fertility and contraceptive issues. Only a few pregnancies in women with PWS are known. Which is the best contraceptive method for PWS woman/ men? What about consent and are there risks of exploitation and abuse? Here, too, on all these matters we would like to hear of your experience.

The roundtable is aimed primarily at professionals and caregivers. As soon as we have the list of registration with the contact details, we will ask all participants to fill in a questionnaire. The answers to this questionnaire will then provide an important basis for the discussion.