# Puberty & Hormone Health in PWS

**What is hypogonadism?**
Hypogonadism is a condition in which the body does not produce enough sex hormones, such as testosterone or estrogen. It is very common in people with Prader-Willi syndrome.

Because of hypogonadism, puberty may begin later than expected, progress more slowly, or remain incomplete without treatment.

**Why does it matter?**
Sex hormones do much more than support puberty and sexual development. Healthy hormone levels also play an important role in:

- Building and maintaining strong bones
- Supporting muscle mass and strength
- Maintaining healthy body composition
- Supporting energy and physical function
- Promoting overall health and well-being

Without adequate sex hormones, people with PWS may have a greater risk of low bone density, osteoporosis, fractures, reduced muscle mass and increased body fat.

Hypogonadism can be effectively treated. An endocrinologist can monitor pubertal development and determine whether testing or hormone replacement therapy may be appropriate.

## When should we start the conversation?

Because delayed or incomplete puberty is common in PWS, families should begin talking with their care team around the usual age of puberty:

**Girls: around age 10**
**Boys: around age 12**

Your endocrinologist can help determine whether further evaluation is needed.

**What is hormone replacement therapy?**
When hypogonadism is diagnosed, treatment replaces hormones the body is not making. This can support pubertal development, bone density, muscle mass and strength, body composition and overall well-being.

**Testosterone replacement**
For boys and men with low testosterone, treatment may include injections, a patch or gel, or oral medication. Treatment often begins with a low dose and increases gradually over time.

**Estrogen + progesterone replacement**
For girls and women with low estrogen, treatment may begin with an estrogen patch or pill. Doctors often start with a low dose and increase it gradually. Progesterone may be added later.

**Treatment is individualized.**
Your endocrinologist will consider age, stage of puberty, hormone levels, medical history and individual needs when recommending and monitoring treatment.

**Hormone health continues into adulthood.**
For many people with PWS, hypogonadism is lifelong. Healthy sex hormone levels help support bone density, muscle mass and strength, energy, body composition and overall well-being throughout adulthood. Regular follow-up with an endocrinologist can help ensure treatment continues to meet changing health needs.

### Will testosterone affect behavior?

Behavior changes are a common concern. Starting with a low dose and increasing gradually may help minimize problems.

### What about periods?

Estrogen treatment may lead to menstruation. Your healthcare team can discuss options for managing the timing and frequency of periods.

**Want to learn more about puberty & hormone health in PWS?**
Explore evaluation, treatment options, common concerns and hormone health throughout adulthood.

https://www.fpwr.org/puberty-in-prader-willi-syndrome