

Growth Hormone Therapy in PWS



What is growth hormone?

Growth hormone is a naturally occurring hormone made by the pituitary gland. It plays an important role in growth, muscle development, body composition, bone health and metabolism.

People with PWS commonly have growth hormone deficiency. GH therapy is considered a standard part of care for children with PWS.

Research has shown that GH therapy can:

- Support growth and height
- Increase lean muscle and reduce body fat
- Improve strength, stamina and physical function
- Support bone health and motor development
- May support cognitive development and quality of life

When can GH therapy begin?

GH therapy can begin in infancy. Research supports starting treatment early, and many babies with PWS begin within the first several months of life. Treatment should be prescribed and monitored by an endocrinologist, ideally one familiar with PWS.

What about cognition?

Research suggests GH therapy may support cognitive development in children with PWS. Studies have reported benefits in areas including communication, daily living skills and cognitive performance. Earlier treatment may be associated with greater developmental benefit.

Starting + Monitoring GH Therapy

Before beginning treatment, your healthcare team will evaluate your child's health and establish important baselines.

Your care team may monitor:

- Growth, weight and body composition
- IGF-1 levels
- Thyroid function
- Blood sugar and metabolic health
- Sleep and breathing
- Airway, tonsils and adenoids, if there are breathing concerns
- Response to treatment and possible side effects

Sleep + breathing

Sleep-disordered breathing is common in PWS. Sleep and breathing should be evaluated before starting GH and monitored during treatment. Depending on age, symptoms and medical history, your care team may recommend a sleep study.

Keep regular follow-up appointments

Monitoring helps your care team track how treatment is working and adjust the dose as needed.

Possible side effects

Growth hormone is generally well tolerated, but side effects can occur. Contact your healthcare team about new or concerning symptoms such as swelling, persistent headaches, hip or knee pain, or worsening sleep or breathing.

How is GH given?

GH is given as a daily injection under the skin, typically at bedtime using an injection pen or similar device.

Your healthcare team will show you how to give the medication and choose injection sites.



Growth Hormone in Adulthood

Research in adults with PWS has shown benefits including improved body composition, increased lean muscle mass and improved physical function.

Why can access be harder for adults?

In the U.S., GH is approved specifically for children with PWS. Adults may need additional testing or documentation to qualify for treatment or insurance coverage.



Having trouble accessing GH?

Peer-reviewed research can help support conversations with your endocrinologist or an insurance appeal.

- Ask what testing or documentation your insurer requires
- Ask your endocrinologist to document the benefits of continued GH therapy
- Include research specific to GH use in adults with PWS

Additional Resources

General Growth Hormone

- [Human Growth Hormone Dosing for PWS](#)
- [Considering Growth Hormone Therapy? Here's What We Know](#)
- [Cognitive advantages of GH treatment in children with PWS](#)
- [Study Confirms GH for PWS Does Not Worsen Scoliosis](#)

Growth Hormone in Adults

- [The Importance of Human Growth Hormone for Adults With PWS](#)
- [Growth hormone treatment of adults with Prader-Willi syndrome](#)
- [Three years of growth hormone treatment in young adults with PWS](#)

The Foundation for Prader-Willi Research funds innovative research and builds resources to accelerate treatments and improve lives.

Learn more about growth hormone therapy in PWS:

<https://www.fpwr.org/the-importance-of-growth-hormone-therapy-for-pws>

