

Research shows positive results and a good safety profile for Growth Hormone therapy.



New Prader-Willi Syndrome Diagnosis

What is Prader-Willi Syndrome?

- Prader-Willi Syndrome (PWS) is a rare genetic disorder affecting approximately 1 in 15,000 births.
- PWS occurs randomly and results from an abnormality of chromosome 15.
- Common characteristics include: hypotonia, low lean muscle mass, hyperphagia and intellectual disability.
- Currently there is no cure for Prader-Willi syndrome.

What should I do next?

- Begin Growth Hormone therapy - **learn more about growth hormone therapy on the next page.**
- Initiate meetings with local early intervention programs
- Download [First Steps: A Parent's Guide to Prader-Willi Syndrome](#) from FPWR.org

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Benefits of Growth Hormone Therapy for PWS

Human growth hormone is effective for increasing height, decreasing body fat, increasing muscle mass, improving weight distribution, increasing stamina, and increasing bone mineral density in PWS. In addition to these positive effects on growth and body composition, studies suggest positive effects on development and behavior.

There is increasing evidence that HGH treatment improves cognitive performance in children with PWS. A study in 2016 by Dykens and colleagues [[Cognitive and adaptive advantages of growth hormone treatment in children with Prader-Willi syndrome](#)] showed that children with PWS who received HGH had higher IQ scores and better communication and daily living skills than children who did not. As with [other studies](#), the results from the Dykens study suggest that "earlier is better": children starting HGH before 12 months of age had higher IQ scores compared to children who started HGH at ages 1–5.

Research Shows Positive Results and a Good Safety Profile

The research on HGH therapy supports its benefits when used for PWS treatment, while continuing the trend of a [reassuring safety profile](#). Scoliosis is very common in PWS, and some physicians may be concerned about HGH use in individuals with PWS who develop scoliosis. But the data suggests that HGH does not worsen scoliosis outcomes; if anything, it is associated with better outcomes, perhaps due to strengthened muscles. HGH may cause tonsils to grow, which can worsen obstructive sleep apnea, and thus a sleep study is recommended before and shortly after starting HGH, with involvement of an ears, nose and throat doctor to address enlarged tonsils, as needed.


Guidelines for Use of Growth Hormone

International consensus guidelines for the use of human growth hormone in PWS were published in 2011. [These published guidelines can be used by medical professionals as a guide for treatment using HGH](#). A helpful [algorithm for initiating HGH therapy is also available here](#).

FREE EBOOK

FIRST STEPS

A Parent's Guide to Prader-Willi Syndrome



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