

# Growth Hormone Deficiency (GHD): A Guide for Talking With Your Healthcare Team

## For Parents, Caregivers, and Families of Children Diagnosed With GHD

CREATED TO SUPPORT MEANINGFUL CONVERSATIONS AND DECISIONS ABOUT TREATMENT

### Understanding Growth Hormone Deficiency

Growth hormone deficiency (GHD) happens when the pituitary gland doesn't make enough growth hormone. This can affect a child's height, strength, bone development, and energy levels.

GHD may be present from birth (congenital) or develop later (acquired). While it's a treatable condition, deciding whether and how to treat it is personal and depends on many factors.

### How GHD May Affect My Child

- Shorter than peers or slower growth over time
- Younger looking than peers
- May appear chubby with increased fat around abdomen
- Shorter than siblings and family genetic potential
- Delayed tooth development
- Delayed puberty or bone development
- Decreased muscle mass or energy
- Emotional or self-esteem concerns related to height
- Newborns may present with jaundice (yellowish skin), a small penis in boys (micropenis), or midline facial defects such as a cleft palate

Every child's experience is different. Some children may have mild symptoms, while others have more noticeable challenges.

### Did You Know?

You might hear about growth hormone being used by athletes or bodybuilders, but that's very different from the medical treatment of GHD. In GHD, growth hormone is replacing something the body isn't making enough of, which is important for normal growth and development. Using growth hormone without a medical need can be unsafe and is not recommended—it doesn't provide the same health benefits and may cause harmful side effects.

### How Is GHD Diagnosed in Children?

Healthcare providers (HCPs) use a few key tools to figure out if your child might have GHD. Here's a quick breakdown:

#### Growth Checks

- HCPs track a child's growth by plotting their height on growth curves, which have percentiles based on age and gender
- If your child is significantly shorter than average, HCPs may take a closer look. Specifically, they'll be concerned if:
  - Your child's height is below the curve for height percentile
  - Your child's height is not tracking at the appropriate height percentile for the family based on "mid-parental target height"—which is a prediction based on how tall mom and dad are. If they're much shorter than what's expected for your family, it may be a red flag.

HCPs also track how fast your child is growing. Specifically, they'll be concerned if:

- Your child's height percentiles are dropping, this is concerning enough for an evaluation

In summary, if your child is much shorter than most peers, growing more slowly than before, or falling further behind on the growth chart, your HCP may consider testing for GHD

- An X ray of your child's left wrist may show that their bones are less mature than their actual age (>2 SD below chronological age)
- Not all short stature means growth hormone deficiency. HCPs also check for:
  - Thyroid issues
  - Genetic conditions like Turner syndrome
  - Chronic illnesses like kidney problems or celiac disease
  - Poor nutrition
  - Simple lab tests and genetic evaluations can help rule these out.
- Your HCP may run additional tests like IGF-1 to screen for GHD; if the levels of these are low, GHD is suspected
- If the IGF-1 levels are low, your HCP may recommend a growth hormone

stimulation test (GST)

- A GST is done after your child fasts overnight
- During the test, medications like arginine, glucagon, clonidine, or DOPA are given to help trigger the body to release growth hormone
- Blood is then taken several times to measure how much hormone is released; if the highest level after 2 different medications is less than 10 ng/mL (some clinics may use a lower number), it may confirm a diagnosis of GHD
- A GST is generally very safe. However, your HCP will monitor closely for symptoms such as low blood sugar, low blood pressure, or nausea and vomiting, which can happen during the test; low blood sugar can present with lightheadedness, sweating, and nausea, and low blood pressure can also present with lightheadedness or drowsiness

Depending on the cause of GHD and associated symptoms, your HCP may recommend a repeat GST as your child gets close to their final adult height to assess if your child needs to continue growth hormone treatment as an adult

## Goals of Treatment

- Improved growth in height of the child, resulting in an average final adult height
- Promote normal physical development
  - Normal muscle and bone development are supported by proportional body composition, including increasing lean body mass and reducing fat mass
- Improved metabolism, cardiovascular health, and bone health
- Improved psychosocial well-being and quality of life

## Treatment Options for GHD

Treatment	What to Know	What It May Involve
Daily Growth Hormone (GH) Injections	The most common treatment for GHD	Given under the skin each night at home
Weekly GH Injections	Newer option with less frequent dosing	Given under the skin once a week at home
Watchful Waiting (only during diagnostic workup or if there is diagnostic uncertainty)	Monitoring growth without immediate treatment during initial phases until a diagnosis is reached	Regular check-ins with your healthcare team
Supportive Care	Focuses on nutrition, activity, and emotional support	Does not include hormone therapy



Talk to your care team about what each option means for your child's growth, lifestyle, and long-term health.

## Things to Think About When Deciding

### Ask yourself and your child (if age-appropriate):

- How important is it to reach a taller adult height (appropriate to the family genetic potential)?
- How much do other benefits of treatment—such as stronger bones, healthier weight, or increased energy—factor into your decision to treat your child's GHD?
- How does my child feel about their growth and appearance?
- Do we have support for giving injections?
- Can we afford the treatment (and is it covered by insurance)?
- What are the risks of not treating now?

## Questions to Ask Your HCP

- What type of GHD does my child have?
- What are the benefits and risks of growth hormone therapy?
- How soon will we see changes if we start treatment?
- What is the difference between daily and long-acting injections?
- Are weekly injections an option for us?
- How long will treatment last? Does my child need treatment their lifetime?
- What happens if we wait or choose not to treat?
- Is my child eligible for any financial support or programs?

## What Matters Most to Our Family? *(Check all that apply)*

- |   |  |
|---|--|
| <input type="radio"/> Helping my child grow taller        | <input type="radio"/> Minimal impact on daily life         |
| <input type="radio"/> Fewer needles/injections            | <input type="radio"/> Cost and insurance coverage          |
| <input type="radio"/> Avoiding long-term medication       | <input type="radio"/> Monitoring and reassessing over time |
| <input type="radio"/> Emotional well-being and confidence | <input type="radio"/> Other: _____                         |

## Making a Choice

There's no one "right" answer. What's best for one child may not be best for another. You may choose to start treatment, wait and monitor, or explore new options later.

### Our Current Plan

Treatment decision   ☐ Daily GH   ☐ Weekly GH   ☐ Wait and monitor   ☐ Supportive care only

Next steps   \_\_\_\_\_

Follow-up date   \_\_\_\_\_

### My Notes & Questions

(Use this space to write down questions or thoughts before your next appointment.)

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**You Are Not Alone** Ask your HCP about:

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|--|--|
| <ul style="list-style-type: none"><li>• Endocrinology nurse support</li><li>• Insurance counseling</li></ul> | <ul style="list-style-type: none"><li>• Patient support programs: The Magic Foundation</li><li>• Online parent communities</li></ul> |
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**This guide is designed to help you make informed choices  
with your child's care team.**

**Talk openly, ask questions, and revisit your decision  
as your child grows and changes.**