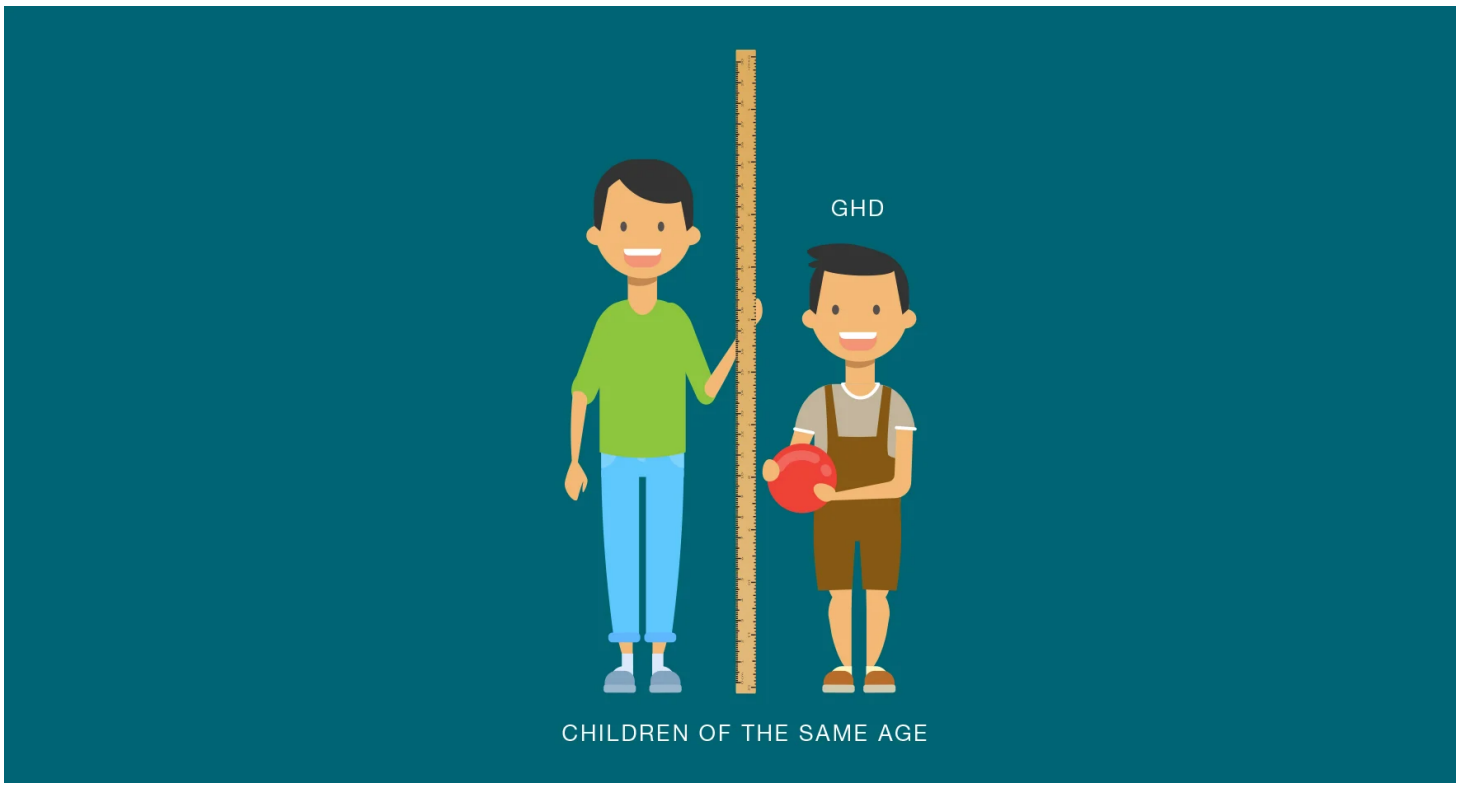

PATIENT RESOURCES

Growth Hormone Deficiency

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español >

Growth hormone deficiency (GHD) is a rare condition in which the body does not make enough **growth hormone (GH)**. Human growth hormone (GH) is a substance that controls children's growth. Among children with short stature, GHD happens in approximately 1:4,000 to 1:10,000 cases.

Endocrine Connection

GH is made by the pituitary gland, a small organ at the base of the brain. In children, GH is essential for normal growth, muscle and bone strength, and distribution of body fat. It also helps control glucose (sugar) and lipid (fat) levels in the body. Without enough GH, a child is likely to grow slowly and be much shorter than other children of the same age and gender.

GH works through a growth factor called insulin-like growth factor 1 (IGF-1). GH stimulates the liver to produce IGF-1 and release it into the circulation. IGF-1 then works at multiple tissues, like bone and cartilage, to promote growth. In addition, GH produces IGF-1 locally at tissues such as bone and cartilage.

Some children are born with GHD (congenital), while others develop it after birth (acquired). Children with congenital GHD may lack additional hormones produced by the pituitary gland. Some children with congenital GHD are found to have mutations (errors in the genes) that involve the development of the pituitary gland or GH production and action. In certain instances, congenital GH deficiency also can be seen as part of a syndrome that may affect the development of the middle of the face.

GHD may develop during childhood or adulthood (acquired GHD) after any process that can damage the pituitary gland or the surrounding brain area. Causes of acquired GHD include brain tumor, surgery, severe brain injury, or radiation of the area that is usually given for treatment of cancer. Rarely, acquired GHD can be the result of a chronic inflammation of the pituitary called hypophysitis, a condition that can be seen after treatment with certain cancer medications. In all these cases, the individual may have additional deficiencies of other pituitary hormones.

Most children with childhood-onset GHD have no additional hormone deficiencies, and doctors cannot find any cause for GHD. These cases of acquired GHD are also called isolated or idiopathic and are not inherited. For some children, slow growth is not caused by GHD. There are many reasons for slow growth and below-average height in children. At times, slow growth is normal and temporary, such as right before puberty starts. A pediatric endocrinologist (children's hormone specialist) or primary care doctor can help find out why a child is growing slowly. Most children with GHD grow less than two inches (5 centimeters) each year.

▸ Diagnosis and Prevention

The single most important clinical sign of GHD in children is growth failure. Children with GHD have severe short stature with normal proportions and appropriate body weight. Review of their growth chart usually shows a drop in height across two or more percentiles.

Your doctor will review your child's medical history and growth charts and look for signs of GHD and other conditions that affect growth. Your doctor may do tests to help find the cause of slow growth. These include:

X-Ray: An X-ray of the hand and wrist, called bone ageto assess growth potential in children.

Blood Tests: A doctor may order a blood test to rule out other conditions that affect growth.

IGF-1 levels: Additional blood work testing for levels of growth factors, such as Insulin-like growth factor (IGF-1) and insulin-like growth factor binding

protein-3 (IGFBP-3), are helpful in diagnosing GHD.

GH stimulation test: During this test, the child is given medicines that stimulate the pituitary to release GH. If GH levels in the blood don't rise to a certain level, it can mean that the pituitary is not making enough GH.

Magnetic resonance image (MRI): An MRI (imaging test) of the head is usually done in individuals with GHD to look for a problem with the pituitary or the brain.

If IGF1 levels are low in the blood test, it may indicate that the person may have GHD. However, there are additional causes of low IGF1 levels, such as liver disease or low body weight.

▸ **Symptoms and Risk Factors**

Common symptoms that are present with a diagnosis of growth hormone deficiency include:

- Short stature and/or slowed growth in height in children.
- Low blood glucose levels in infants and toddlers.
- Children with GHD and additional pituitary hormone deficiencies may have extra signs, such as a very small penis in newborn males or absence of puberty during teenage years.
- Children with congenital GHD because of a syndrome may have additional symptoms such as blindness.

Babies with severe congenital GHD usually have only a slightly reduced birth length and may not immediately show signs of slow growth. In these

children, a low blood sugar can be the main sign of GHD.

Adults with severe GHD may also experience:

- An increase in body fat distribution with extra weight around the waist
- A decrease in muscle bulk and strength
- Low energy levels
- Abnormalities in cholesterol levels
- Increased risk for fractures

Irradiation, surgery or injury to the pituitary area of the brain can increase the chance of developing acquired GHD. Untreated children with GHD reach a short adult height. Untreated GHD in adults may increase risk for heart disease and fractures.

Treatment and Therapies

People with GHD receive treatment with daily injections of synthetic (manufactured) human GH, a prescription medicine. GH is given at home as an injection under the skin at bedtime. More recently, a sustained – release GH that is given as a weekly injection under the skin has become available.

Individuals treated with GH need regular doctor check-ups. In children, your doctor usually monitors the growth response to GH and changes in IGF1 levels in the blood and bone age x ray.

GH therapy is effective in improving growth and results in a normal adult height. The best results occur when GHD is diagnosed and treated early. In

some children, GH can lead to four inches (10 centimeters) of growth during the first year of treatment. Therapy can continue until the child completes his/her growth and reaches adult height. At that point, the individual can be re-tested to see if he/she should continue GH therapy as an adult. Most of the childhood-onset cases of isolated GHD do not need therapy in adult life.

In children, mild to moderate side effects are uncommon. They include:

- Headaches
- Muscle or joint pain
- Mildly under active thyroid gland
- Swelling of hands and feet
- Worsening curvature of the spine (scoliosis)

Rare but serious side effects include:

- Severe headache with vision problems
- A hip problem - when the top of the thigh bone slips out of place
- Inflamed pancreas (pancreatitis)
- Sleep apnea (i.e. blockage of upper airway during sleep) can happen in people with certain genetic conditions, such as Prader Will syndrome.

For most children, the benefits of taking GH outweigh the risks. In adults, the GH side effects are also rare and can be swelling of hands and feet, joint pains and carpal tunnel syndrome. An increase risk for type II diabetes can happen in people with certain genetic predisposition such as Prader Will syndrome.

Concerns have been raised about a possibility that GH may increase an individual's cancer risk. Several studies so far point out that GH treatment for individuals with GHD does not increase the risk for leukemia or other cancers compared with age-matched healthy people.

You can help your child get the best care for GHD by taking these steps:

- Call the doctor if you have questions about treatment.
- Follow directions carefully when giving GH and other prescription medicines to your child.
- Tell all of your child's doctors that your child takes GH.
- Be sure your child gets frequent checkups.

▸ **Questions For Your Healthcare Provider**

- What should my child's height be at this age?
- Why is my child growing slowly?
  Does my child need treatment for GHD?
- If so, how, and when do I give my child the shots?
- Should we see a pediatric endocrinologist?