

# Growth Hormone Deficiency: A Guide for Families

## What is growth hormone deficiency?

Growth hormone deficiency is a rare cause of growth failure in which the child does not make enough growth hormone to grow normally. Growth hormone is one of several hormones made by the pituitary gland, which is located at the base of the brain behind the nose.

## How frequent is growth hormone deficiency?

Estimates vary, but it is rare. The incidence is less than one in 3000 to one in 10,000 children.

## What causes growth hormone deficiency?

There are many causes of growth hormone deficiency, most of which are present at birth (called “congenital”) but may take several years to become apparent or it can develop later (called “acquired”). Congenital causes include genetic or structural abnormalities of the development of the pituitary gland and surrounding structures, while acquired causes, which are much less common, can include head trauma, infection, tumor, or radiation.

## What are signs and symptoms of growth hormone deficiency?

Children with growth hormone deficiency are usually much shorter than their peers (that is, well below the 3rd percentile line) and over time, they tend to drop farther and farther below the normal range. It is important to note that growth hormone-deficient children are usually not underweight for their height; in many cases, they are on the pudgy side, especially around the stomach.

## How is growth hormone deficiency diagnosed?

Evaluation of a child with short stature and slow growth pattern may include a bone age x-ray (x-ray of the left wrist and hand) and various screening laboratory tests. The diagnosis of growth hormone deficiency cannot be made on a single random growth hormone level, because growth hormone is secreted in pulses. Some pediatric endocrinologists diagnose growth hormone deficiency based on an extremely low level of insulin-like growth factor 1 (IGF-1), which varies much less in the course of the day than growth hormone. IGF-1 levels are dependent on the amount of growth hormone in the blood but can also be low in normal, young children, so the test must be interpreted carefully.

A more accurate but still imperfect way to diagnose growth hormone deficiency is a growth hormone stimulation test. In this test, your child has blood drawn for about 2 to 3 hours after being given medications to increase growth hormone release. If the child does not produce enough growth hormone after this stimulation, then the child is diagnosed with growth hormone deficiency. However, growth hormone stimulation tests can overdiagnose growth hormone deficiency. Growth hormone stimulation tests vary and are complicated, so they are usually performed

under the guidance of a pediatric endocrinologist. Usually, other tests to check the pituitary or to evaluate the brain (MRI) are performed when treatment is considered.

## How is growth hormone deficiency treated?

The treatment for growth hormone deficiency is administration of recombinant human growth hormone by subcutaneous injection (under the skin) once a day. The pediatric endocrinologist calculates the initial dose based on weight, and then bases the dose on response and puberty. The parent is instructed on how to administer the growth hormone to the child at home, rotating injection sites among the arms, legs, buttocks, and stomach. The length of growth hormone treatment depends on how well the child’s height responds to growth hormone injections and how puberty affects the growth. Usually, the child is on growth hormone injections until growth is complete, which is sometimes many years.

## What are the side effects of growth hormone treatment?

In general, there are few children who experience side effects from growth hormone. Side effects that have been described include severe headaches, hip problems, and problems at the injection site. To avoid scarring, you should place the injections at different sites. However, side effects are generally rare. Please read the package insert for a full list of side effects.

## How is the dose of growth hormone determined?

The pediatric endocrinologist calculates the initial dose based on weight and condition being treated. At later visits, the doctor will change the dose for effect and pubertal stage and sometimes based on IGF-1 blood test results. The length of growth hormone treatment depends on how well the child’s height responds to growth hormone injections and how puberty affects growth.

## What is the prognosis for growth hormone deficiency?

Growth hormone usually results in an increase in height for growth hormone-deficient individuals, as long as the growth plates have not fused. The reason for the growth hormone deficiency should be understood, and it is important to recheck for growth hormone deficiency when the child is an adult, because some children no longer test as if they are growth hormone deficient when they are fully grown.

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