

Understanding Growth Hormone Deficiency

Growth hormone deficiency happens when the pituitary gland in the brain does not make enough growth hormone. This handout will explain growth hormone deficiency, the signs and causes of growth hormone deficiency, how we test for it and how we treat it.

WHAT IS GROWTH HORMONE DEFICIENCY?

Growth hormone deficiency is when the pituitary gland (a small gland in the brain that controls other glands in the body) does not make enough growth hormone. This makes your child grow more slowly.

WHAT ARE THE SIGNS OF GROWTH HORMONE DEFICIENCY?

The most common signs of growth hormone deficiency in childhood are **short stature** (shorter height than usual) and **decreased growth** (growing slower than usual). Children who have growth hormone deficiency might also have the following signs:

- Increased body and belly fat
- Decreased amount of muscle
- High-pitched voice
- Delayed bone age (found through an X-ray called a bone age)
- Low blood sugar (usually in infants and very young children)

WHAT CAUSES GROWTH HORMONE DEFICIENCY?

We often do not know what causes growth hormone deficiency, and every child is different. Some common causes of growth hormone deficiency include:

- When the pituitary gland doesn't develop properly before your child is born
- A mass or tumor that interrupts how the pituitary gland works
- Radiation to treat a brain tumor or other type of cancer in the brain
- Inflammation (swelling) of the pituitary gland
- Genetic diseases that interrupt how the pituitary gland works or develops

HOW DO WE TEST FOR GROWTH HORMONE DEFICIENCY?

We test for growth hormone deficiency in many ways. These are a bone age X-ray, a blood test, growth hormone stimulation testing and a brain MRI. **We test children for growth hormone deficiency ONLY if they not growing properly AND we have ruled out other causes for their slow growth.**

• Bone age

A bone age is an X-ray of the left hand and wrist that measures how mature your child's bones are. Children with growth hormone deficiency often have immature bones relative to their age, which would be called a delayed bone age. For example, your child might be 12-years-old, but his or her bones might have the maturity level expected for a 9-year-old – this would be called a delayed bone age.

• A blood test

For the blood test, we test the levels of 2 proteins in your child's blood. These 2 proteins are called IGF-1* and IGFBP-3**. Your body makes these proteins when your body releases growth hormone. When your child's growth hormone levels are low, the levels of these proteins might also be low.

• Growth hormone stimulation test

For this test, we will give your child medication through an IV (a small tube that goes into a vein). The medication will allow us to check your child's growth hormone levels in the doctor's office every 15-30 minutes for 2-4 hours. **We do this test ONLY when we think there is a high chance that your child has growth hormone deficiency. See the back of this handout to learn more about this test.**

• A brain MRI

A brain MRI is a special X-ray that tells us if your child's pituitary gland is growing normally. It also tells us whether it is safe to treat your child with growth hormone medication.

Growth hormone stimulation testing

For a growth hormone stimulation test, we will insert an IV (a small plastic tube that makes it easier to draw blood and give certain medications) into your child's vein, usually in his or her arm. We will draw a small sample of blood to measure the amount of growth hormone in your child's blood. Then, we will give your child medication through the IV that makes his or her growth hormone levels increase. After we give this medication, we will check the levels of your child's growth hormone every 15-30 minutes for the next 2-4 hours.

We will figure out if your child has growth hormone deficiency if his or her "peak growth hormone," or highest growth hormone level, is below a certain cut-off.

A growth hormone stimulation test takes between 2-5 hours. It is important for us to check your child's growth hormone levels every 15-30 minutes because growth hormone levels change throughout the day.

We only do this test if we think there is a high chance that your child has growth hormone deficiency.

HOW DO WE TREAT GROWTH HORMONE DEFICIENCY?

We treat growth hormone deficiency with a medication called **growth hormone**. The growth hormone acts just like the growth hormone that your body makes naturally. You will usually give your child growth hormone through an injection (a shot) at home. **The needle for the shot is very small.** Many children say they get used to the feeling of the shot after a few times.

HOW LONG DOES MY CHILD HAVE TO TAKE THE GROWTH HORMONE?

You will give your child the growth hormone until he or she has stopped growing. While your child is taking the growth hormone, he or she will need lab tests and doctor visits every 3-6 months. This is to make sure your child is taking the right dose and to make sure there are no side effects.

Many children who have growth hormone deficiency do not have it once they are teenagers. When your child has stopped growing, he or she will most likely go off growth hormone for at least one month. Then, we will retest him or her for growth hormone deficiency. If tests show that he or she still has growth hormone deficiency, your child might start taking a lower dose again once he or she is a teenager.

WHERE CAN I FIND MORE INFORMATION ABOUT GROWTH HORMONE DEFICIENCY?

You can find more information about growth hormone deficiency at these resources:

- **The Human Growth Foundation** is a non-profit organization that supports people with growth disorders. www.hgfound.org
- **The MAGIC Foundation** is a non-profit organization that supports people with conditions and diseases that affect growth. www.magicfoundation.org
- **The National Institutes of Health** is the United States' medical research organization. They keep up-to-date, accurate information about many health topics. www.nih.gov

** IGF-1 means insulin-like growth factor 1*

***IGFBP-3 means insulin-like growth factor binding protein 3*

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