

Small for
Gestational Age (SGA)



Knowledge
to grow by

Models throughout are used for illustrative purposes only.



Introduction

Too short, too tall, or just right? From birth, your health care provider has tracked your child's progress, graphing height, weight, and head size as points on a chart.

Your child's growth curve is consistently below average. Your doctor has explained that your son or daughter has short stature related to birth size being small for gestational age, or SGA. There are lots of reasons for slow growth. In this brochure, you will get answers to your questions about your child's development. You will also get information on what you can do to help your child, so you can make informed decisions now and in the future.

Is your child growing normally?

Your child's growth depends on many factors. Sometimes, kids just grow more slowly than their peers, and there's no particular reason. Also, small parents tend to have small children. Many things can affect growth, including diet and environment. There could be medical reasons for slow growth. One cause is genetic factors. Another is lack of **growth hormone**. We'll go over all of these reasons.

Small for gestational age (SGA)

What is gestational age?

Gestational age refers to how many weeks the **fetus** has been growing inside of the mother's womb. It is based on the date of the mother's last menstrual period. An ultrasound during the first 3 months of pregnancy measuring the head, abdomen, and thigh bone also helps to determine gestational age.

Most babies are born after 38 to 42 weeks of gestation. Right after birth, your doctor checked your child's weight and length, and compared it with the weight and length expected for his or her gestational age. Most babies have a birth length and weight very close to what is expected, but some are larger or heavier than expected, and some are smaller or lighter.

Your doctor may also have looked at other things, such as your baby's head size, the condition of skin and hair, reflexes, muscle tone, posture, and other signs to determine your baby's developmental gestational age. This second number describes the age that your baby actually looks and acts. For example, although your baby may have been born after 39 weeks, he or she may look and act more like a baby born after only 35 weeks.



Both of these gestational ages are important because together they provide valuable information that can directly affect the medical treatment plan for your baby.

What is short stature?

If you are told your child has short stature, or is small for gestational age (SGA), it means that his or her birth weight and/or length was below the 3rd **percentile**. This means that your child is smaller than 97% of all other babies at that gestational age.

Your doctor is able to compare your child's growth with national averages. When your health care provider sees a consistent trend, he or she can look for other signs of SGA.

About 100,000 children born in the United States each year are shorter and lighter than normal, whether or not they are premature or full-term infants. Most children born SGA catch up, but

those with no **catch-up growth** by age 2-3 may need more attention from an **endocrinologist** who is a doctor who specializes in endocrine care.

Why does SGA happen?

Most of the time, we don't know why a child is born SGA. It just happens. When we can locate a cause, the 3 most common reasons are issues with the fetus, including a multiple birth (twins, triplets, etc.) or genetic defect, problems with the **placenta** that do not let the fetus get enough blood, or mother's health issues such as heart disease, malnutrition, or drug, alcohol, or cigarette abuse.

Children born SGA may have a normal amount of growth hormone, or they may have less growth hormone than the average child.

Predicting your child's height

Genetic factors

Blue eyes or brown, light hair or dark, short or tall—our **genes** play an essential role in determining our **characteristics**, including individual color, size, and shape. If smaller-than-average height runs in your family, then it's more likely that your child will be small. Your doctor may say your child has familial short stature.

But the cause may be more complicated. Several genetic **disorders** cause short stature. They include Turner syndrome, Noonan syndrome, and Russell-Silver syndrome. If your doctor thinks your child has one of these disorders, you will be referred to a pediatric specialist for further testing.

Growth hormone deficiency

What do hormones have to do with it?

Hormones are chemical messengers produced in one part of the body that travel through the bloodstream to other parts of the body, where they deliver a message to cause some kind of change in the body.

About growth hormone

Growth hormone is produced by the **pituitary gland**, a pea-sized gland located just under the brain and behind the bridge of the nose. When the pituitary gland receives a message from the brain, it sends growth hormone via the bloodstream to the bones and other parts of the body, creating cell growth and division. The action of growth hormone causes children to grow taller.

How does growth hormone work?

When growth hormone is released from the pituitary gland, it causes the release of a second growth-promoting hormone called **insulin-like growth factor 1 (IGF-1)**.

Together, growth hormone and IGF-1 signal growth and increased number of cells in bone, muscle, and many other organs and tissues. Growing strong bones requires both growth hormone and IGF-1.



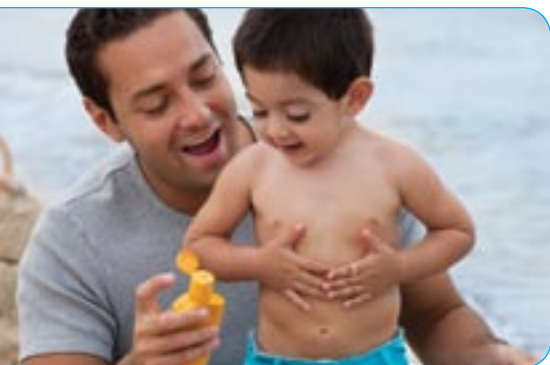
What is growth hormone deficiency?

When the pituitary gland does not produce or release enough growth hormone into the bloodstream, it is called growth hormone deficiency, or GHD. This can be because of a genetic defect, pituitary tumor, traumatic brain injury, or some unknown cause. Children who have GHD and who do not take daily growth hormone therapy will not reach their full growth potential.

The signs of GHD

In children, some signs of GHD are:

- Much shorter height than expected, based on biological parents' heights
- Growth of less than 2 inches per year between the ages of 2 and 11 years in girls or the ages of 2 and 13 years in boys
- Leveling off and slowing of growth rate
- Growth that is below the 3rd percentile on standardized growth charts



How do I know it is GHD?

An endocrinologist can determine if your child has GHD. The doctor will first ask questions about your child's health and growth history, as well as about your family history. Your child will also undergo a complete physical examination. When necessary, the doctor will order blood tests to track the level of growth hormone in your child's blood.

Your son or daughter might also be given a stim test (short for stimulation test) to help diagnose GHD. This is an important test, which can often help your doctor be sure of GHD.

Evaluating and diagnosing SGA Hand X-ray

The doctor may take an X-ray of your child's hand because it shows his or her bone age, and can help predict your child's final adult height. Bone age is more important than actual age in years because it can help to show if your child still has room for catch-up growth.

The stimulation (stim) test

A stim test is a procedure used to determine if your child's pituitary gland, the gland that produces growth hormone, is doing its job. The test **stimulates** the pituitary gland, helping your doctor understand if growth hormone is being secreted in normal amounts.

Preparing for the test

The night before the test, your child should have no food or liquid after midnight. You may receive special instructions depending on your child's health profile.

What to expect

The stim test requires an IV, so dress your child in comfortable, loose-fitting clothing. During the test, your doctor will give your child various medications by needle to see if growth hormone can be produced and released. He or she will also draw blood during the test to see how the growth hormone is responding. The total testing may take several hours.

After the stim test

Test results are generally reported within 1 to 2 weeks by the laboratory to your doctor, who will discuss the results with you. If the results of the stim test show a growth hormone deficiency, your doctor may recommend growth hormone therapy.



Taking action: treatment of SGA

It is important to treat the whole child, mind and body, and provide a supportive atmosphere at home. Later in this brochure, you will find web sites that provide tips on emotional and psychological support.

Your child is no different

Recent studies indicate that children of short stature have pretty much the same social, emotional, and behavioral patterns as children of average height.

Growth hormone therapy

If the results of your child's stim test indicate that he or she has GHD, your doctor may recommend growth hormone therapy. Growth hormone therapy, in the form of daily growth hormone injections administered 6 or 7 times a week, may help kids with GHD to reach their growth potential.

Early treatment

Children under the age of 4 diagnosed with SGA generally respond best to growth hormone therapy.

How do you take growth hormone therapy?

Growth hormone is taken with daily injections. The growth hormone is supplied as delivery pens that look like writing pens with a very short, very thin needle on one end. The cartridges inside the pens contain growth hormone that has been produced to be as close as possible to the growth hormone your child's body makes naturally. Injectable growth hormone contains the identical number of amino acids as the naturally occurring pituitary growth hormone.

Injections are usually done 6 to 7 times per week at the same time every day; for example, at bedtime. Talk to your doctor about the best schedule for your child.

Why an injection?

One of the first things families find out about growth hormone is that it has to be injected. Growth hormone is a peptide. This means it is similar to a protein, like the protein we eat in certain foods. When protein is eaten, the acids in the stomach break it down so it can be digested. If you took growth hormone by mouth—say as a pill or liquid—the same thing would happen. The stomach would break it down and digest it. In a “broken-down” state, it would not be able to help you grow. Growth hormone has to be injected so that it can work properly.

Who will give the injections?

If your child is old enough, he or she might want to give the injections to himself or herself. If your child is not old enough, a parent or caregiver will inject the growth hormone.

Keeping a calendar

Your doctor will carefully monitor your child's growth during treatment, and will adjust the hormone dose as necessary. You may find it helpful to keep a chart at home with notes on your child's progress and dosing information.

Your expectations

Treatment with growth hormone helps children with SGA have catch-up growth.

The effects of growth hormone therapy are different in different children and teens. Your doctor can give you more information about what to expect for your child.

When growth hormone therapy begins early and continues through puberty, some studies have shown that many children with SGA reach a height that's considered normal when compared to healthy children of the same age.



Insurance

Questions about coverage

You may have questions about insurance coverage for GHD treatment. Rest assured that there are programs in place that can help you get the assistance you need. In many cases, assistance is just a phone call away. The manufacturer of your child's growth hormone therapy can answer your questions about insurance coverage and reimbursement, and may be able to help you find additional coverage to ensure that your child's treatment continues smoothly.

Getting help

With your permission, your doctor will contact the pharmaceutical manufacturer so that you can get help with completing insurance paperwork. The doctor will submit a Statement of Medical Necessity, a recent growth chart (if applicable), and any available insurance information.

Manufacturers' assistance programs

If you are unable to resolve insurance reimbursement issues, the pharmaceutical manufacturer may be able to provide growth hormone therapy free of charge on a short-term basis. Once you have a relationship with a representative from the manufacturer, you can get all the information you need to make the right choice for your child and your family. They can also help in finding assistance from other patient and not-for-profit support organizations.

Questions to discuss with your doctor

Here are some examples of questions that you may want to ask your doctor about GHD and growth hormone therapy in order to make your office visit more effective:

- How long will my child have to take growth hormone?
- Are there any side effects involved in growth hormone therapy?
- What are the consequences of not being on growth hormone therapy?
- How do I take growth hormone?
- Will the injection hurt?
- My child does not like needles. What can I do?
- How can I be trained on growth hormone therapy?
- Are there any pre-existing medical conditions that can interfere with growth hormone therapy?
- Who gives the injection?
- How do I store my growth hormone?

ADDITIONAL RESOURCES

You can also find information and support from these organizations:

The Hormone Foundation

The public education affiliate of The Endocrine Society

8401 Connecticut Avenue, Suite 900

Chevy Chase, MD 20815-5817

Tel: 1-800-HORMONE (467-6663)

hormone.org

Human Growth Foundation

997 Glen Cove Avenue, Suite 5

Glen Head, NY 11545

Tel: 1-800-451-6434

hgfound.org | hgf1@hgfound.org

The MAGIC Foundation

6645 W. North Avenue

Oak Park, IL 60302

Tel: 1-800-3MAGIC3 (362-4423)

magicfoundation.org

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

National Institutes of Health, DHHS

31 Center Drive, Bldg. 31

Rm. 2A32 MSC 2425

Bethesda, MD 20892-2425

Tel: 301-496-5133

nichd.nih.gov

Pituitary Network Association

P.O. Box 1958

Thousand Oaks, CA 91358

Tel: 805-499-9973

pituitary.org

Regional Support Groups at:

pituitary.org/support

GLOSSARY

Here are definitions for some words in this brochure that may be new to you. If there are other words you need to understand better, your child's doctor or nurse can help you.

Catch-up growth

Catch-up growth means the ability to catch up to the average height of normal children. Most children born SGA will have their catch-up growth by age 2, but some do not. Growth hormone may help your child have his or her catch-up growth.

Characteristic

A distinguishing trait, quality, or property.

Disorder

An abnormal physical or mental condition.

Endocrinologist

A specially trained doctor who diagnoses and treats diseases of your glands and hormone imbalances.

Fetus

A developing human from 2 months of gestation to birth.

Genes

The functional units on a chromosome that transmit characteristics from parents to their children. Short pieces of DNA tell the body how to build a specific protein. There are approximately 30,000 genes in each cell of the human body. The combination of all genes makes up the blueprint for the human body and its functions. A person's genetic makeup is called a genotype.

Gestational age

The time measured from the first day of the woman's last menstrual cycle to the current date. It is measured in weeks. A normal pregnancy can range from 38 to 42 weeks. Gestational age can be determined before or when the baby is born.

Growth hormone

A hormone produced by the pituitary gland that promotes growth in humans. It occurs naturally in the body as somatotropin. When given as injectable growth hormone therapy, it is known as somatropin, and contains the identical number of amino acids as somatotropin.

IGF-1

Stands for insulin-like growth factor 1, a growth-promoting hormone. Growth hormone causes organs in the body to make IGF-1, which in turn causes cell growth.

Percentile

A measurement that tells how much of a group is equal to or below it. For example, a percentile score of 95 is a score equal to or better than 95% of other scores.

Pituitary gland

A pea-sized gland located just under the brain and behind the bridge of the nose. The pituitary gland produces and sends growth hormone via the bloodstream to the bones and other parts of the body, creating cell growth and division.


Placenta

The placenta grows around the fetus during pregnancy and stays connected to the wall of the uterus. It provides the fetus with nourishment and secretes hormones that help regulate and maintain the pregnancy.

Stimulate

To temporarily increase activity.

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