

# Idiopathic Short Stature



**Knowledge**  
to grow by



## Idiopathic short stature

Chances are if both parents are below average height, your child will also be on the short side. However, if a child is diagnosed with Idiopathic Short Stature (ISS), it's not related to how tall or short his or her parents are. Idiopathic is a big word that means no known cause. ISS is defined as a height that's significantly shorter than the average population without a diagnostic explanation.

If you think your child isn't growing normally, you should see a pediatrician who may suggest you meet with a child growth specialist known as a pediatric endocrinologist. A **pediatric endocrinologist** is a doctor trained to diagnose and treat children with growth disorders.



### What is ISS?

The term ISS is used when your child is very short compared with other children of the same age and there doesn't appear to be a disorder, hormonal issue, or nutritional problem that would cause it. Children with ISS often remain short into adulthood.

Normal growth in children is the result of nutrition, genetics, and hormones. The average length of a newborn is 20 inches. After 1 year, the average height is 30 inches. At 2 years, about 35 inches; 4 years, about 40 inches. After 4 years, linear growth averages about 2 inches per year until **puberty**.

### What are the signs of ISS?

If you only look at a child's weight or levels of **growth hormone**, it's difficult to diagnose ISS. Children with ISS have normal birth weights and sufficient levels of growth hormone, which means they do not have **growth hormone deficiency** (GHD). Most children with ISS have normal body proportions. Often, short **stature** is the only noticeable difference. If your child is diagnosed with ISS, there are medicines that may help.

Children with ISS are shorter than other children of the same age. They may have a growth curve that is below the third **percentile** or show growth rates that would result in an adult height below the normal range.

### Signs of ISS:

- Shorter height than the normal range, regardless of biological parents' heights
- Height that is below the third percentile (smaller than 97% of other children the same age)



## How is ISS diagnosed?

In order to diagnose your child with ISS, your child's pediatric endocrinologist must first rule out other causes of short stature, such as GHD or a genetic disorder. Your child's doctor will conduct a thorough physical exam, which may include lab tests, along with measuring your child's height, arm span, and head circumference for those under 4 years of age. Depending on the results of the examination, your child's doctor may suggest further testing—this may include genetic testing.

Your child's pediatric endocrinologist may also order a **stimulation** test, or "stim test," to measure your child's level of growth hormone. During this test, your child is given a medication that causes the **pituitary gland** to release larger amounts of growth hormone. Over a period of time, several blood samples are taken to measure the amount of growth hormone in the body. If your child's growth hormone levels are normal, the diagnosis may be ISS.

In most cases, ISS is diagnosed by ruling out growth hormone deficiency as the cause of your child's short stature.

## Treatment

If your child is diagnosed with ISS, the pediatric endocrinologist will recommend certain treatments with the goal of helping your child achieve normal adult height. Your child's pediatric endocrinologist can give you more information about treatment options and possible outcomes to expect.

To learn more about treatments for your child, speak with your child's pediatrician or pediatric endocrinologist.

## Follow-up visits

After diagnosing your child with ISS, the doctor will likely schedule regular follow-up visits. The doctor will monitor your child's growth to make sure that treatment is working well.

## Support your child

The self-esteem of children with short stature has much to do with how they see their bodies. Children who feel good about themselves and who feel loved by their families may feel fine about their short stature.

**Remind your child that a person's worth has nothing to do with height.**



## Insurance

### Questions about coverage

If your child is prescribed treatment, you may have questions about insurance coverage. There are programs that may help you get the assistance you need. The manufacturer of your child's treatment may be able to answer your questions about insurance coverage and reimbursement, and may be able to help you find additional options to ensure that your child's treatment continues as prescribed.

### Getting help

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

### Manufacturers' assistance programs

If your child's doctor has prescribed a treatment option for your child but you are unable to resolve insurance reimbursement issues, the pharmaceutical manufacturer may be able to provide treatment free of charge on a short-term basis. There may also be assistance available from other support organizations.

## Additional resources

You can find information and support from these organizations:

### Hormone Health Network

The public education affiliate of  
The Endocrine Society  
8401 Connecticut Avenue, Suite 900  
Chevy Chase, MD 20815-5817  
Tel: 1-800-HORMONE (1-800-467-6663)  
[hormone.org](http://hormone.org)

### Human Growth Foundation

997 Glencove Avenue, Suite 5  
Glenhead, NY 11545  
Tel: 1-800-451-6434  
[hgfound.org](http://hgfound.org) | [hg1@hgfound.org](mailto:hg1@hgfound.org)

### The MAGIC Foundation®

4200 Cantera Drive, #106  
Warrenville, IL 60555  
Tel: 1-800-3MAGIC3 (1-800-362-4423)  
[magicfoundation.org](http://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  
Bethesda, MD 20892-2425  
Tel: 1-800-370-2943  
[nichd.nih.gov](http://nichd.nih.gov)

### Pituitary Network Association

P.O. Box 1958  
Thousand Oaks, CA 91358  
Tel: 1-805-499-9973  
[pituitary.org](http://pituitary.org)  
*Regional support groups at:*  
[Pituitary.org/support-groups](http://Pituitary.org/support-groups)

## **Glossary**

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

### **Growth hormone**

A hormone produced by the pituitary gland that promotes growth in children.

### **Growth hormone deficiency**

A disorder in which the body does not make enough growth hormone.

### **Pediatric endocrinologist**

A specially trained doctor who diagnoses and treats diseases of the glands and hormone imbalances in children.

### **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 greater than 95% of other scores.

### **Pituitary gland**

A pea-sized gland located at the base of the brain. The pituitary gland produces and sends growth hormone via the bloodstream to the bones and other parts of the body.

### **Puberty**

The growth period during sexual maturity.

### **Stature**

The standing height of a person.

### **Stimulation**

Temporary increase in activity.

**Knowledge To Grow By,  
brought to you by Novo Nordisk.**

Novo Nordisk is a registered trademark of Novo Nordisk A/S.

All other trademarks, registered or unregistered, are the property of their respective owners.

© 2020 Novo Nordisk All rights reserved.

US20GH00070 December 2020

