

# Understanding Growth Disorders



Individuals depicted  
in this brochure are  
not actual patients.



# Growing Your Awareness

## Growth Hormone Deficiency



### What do “normal” milestones look like?

Generally, children reach certain height milestones at certain times, but these can vary. If you are concerned about your child’s growth, speak with his or her doctor. From 2 to 3 years of age, children grow around 3.5 inches a year. From 3 to 4 years of age, children grow around 2 inches a year. Most children will have doubled their birth height by the time they are 4 years old. Steady growth continues until puberty, which is a time of rapid growth spurts that are unique to each child.

### How do doctors measure growth?

During office visits, your doctor measures your child’s growth and records it on a growth chart, a tool that compares your child’s growth to the growth of other children the same age.

Normal variations are measured in “percentiles.” For example, if your child is in the fifth percentile in height, that means that 95% of children are taller, but your child may still be in the normal range.

### What is growth hormone deficiency?

Growth hormone deficiency, or GHD, happens when a child’s body doesn’t make enough growth hormone on its own. Growth hormone helps children grow to their full height potential. One sign of GHD is noticeable slowing of growth. Between age 2 and puberty, children with GHD may grow less than 2 inches per year. Children with GHD are smaller than others of their age and sex. They may also look younger. But their bodies look normal in all other ways.

### What might my health care provider recommend?

If your child’s growth is not in the normal range, your doctor may do more tests, such as a growth hormone (GH) stimulation test, also called a stim test. He or she may also refer you to a pediatric endocrinologist, a doctor who specializes in growth disorders.

### What to expect if your doctor recommends a GH stimulation test for your child?

- An intravenous (IV) needle will be placed into your child’s arm or hand. This helps the doctor or nurse to collect more than one blood sample with only one needle prick
- A medicine will be given to your child through the IV to help your child’s body release growth hormone
- Blood samples will also be taken from this IV at different times over a few hours
- After the test, the blood samples will be sent to a laboratory to determine if your child’s body produced the expected amount of growth hormone
- The doctor or nurse can tell you about any possible side effects of the test. For example, your child may feel tired and want to rest after the test

# Idiopathic Short Stature

## What is idiopathic short stature?

Idiopathic short stature, or ISS, is a growth problem in children. Children with ISS are shorter than 98.8% of other children of the same age and sex. They are growing at a rate so slow that they will most likely not be able to reach their normal adult height.

No one knows what causes ISS. Scientists are working to find out why some kids have growth problems. They have made progress, but they still have not found a cause for growth failure in these children.

The diagnosis of ISS is made once all other causes of growth delay have been excluded.

## How does my child's doctor know if my child has ISS?

Your child's health care provider should measure your child at each annual checkup and mark it on a chart, comparing your child's growth to other children's. If your child's growth is not keeping up with most other kids, there are tests that may be able to show why.

### These tests include:

- Blood and urine tests to help rule out other disorders that could affect growth

# Prader-Willi Syndrome



## What is Prader-Willi syndrome?

Prader-Willi (PrAh-dur WILL-ee) syndrome, or PWS, is a complex disorder caused by changes in certain genes. It is rarely inherited, but occurs when the fetus is forming.

### Some of the signs of PWS are physical:

- Weakness and feeding problems in infancy
- Uncontrollable hunger
- Poor muscle tone
- Deep-set, almond-shaped eyes
- Short stature
- Small hands and feet
- Incomplete sexual development
- Vision problems

### Other signs of PWS have to do with behavior and learning issues:

- Delayed language development
- Learning problems
- Sleep problems
- Unpredictable emotional outbursts
- Skin picking
- High pain threshold

## Living with PWS

PWS cannot be cured, but there are ways to help with many of the symptoms. There are special therapists who can help with your child's weakness and muscle tone. Your child can get special training in social skills to help with behavior problems. To help prevent obesity, you may need to limit the amount of food your child can have. Many families keep their children on special meal plans.

# Small for Gestational Age

## What is small for gestational age?

Small for gestational age, or SGA, is used to describe a child born smaller in size than normal for the child's sex and gestational age (the number of weeks of pregnancy at birth). SGA children are smaller than most kids who were born after the same number of weeks of pregnancy. Often, it is unclear why a baby is born SGA. Sometimes a fetal growth problem occurring during pregnancy is a cause, as well as genetic factors.

## Do SGA babies stay small?

Most children born SGA “catch up” to other children by age 2. They catch up by growing faster than usual during the first 2 years. But 15% of these children don't catch up by age 2. These children may be helped by growth hormone therapy.

## How does my child's doctor know if my child is SGA?

Your child's health care provider should track growth using standard charts. These charts contain curved lines that are the average growth rates of US children. Your child's health care provider measures your child at each checkup and marks the chart. With SGA children, the health care provider sees that the child's growth is not keeping up with most other children.

If your child is not catching up by age 2, there are tests that may be able to show why.

### These tests include:

- A full physical exam
- Blood and urine tests to help rule out other disorders that could affect growth

# Turner Syndrome



## What is Turner syndrome?

Turner syndrome, or TS, is a complex disorder. It is caused by changes in or absence of one of the X chromosomes. It affects only girls. About 1 out of every 2500 girls born each year is affected by TS. There can be many features with TS; not all girls with TS will have all of these features, and the features may be more serious in one patient and less serious in another.

Almost all girls with TS have short stature and loss of ovarian function.

### Other symptoms of TS may include:

- Puffy hands and feet at birth
- Low hairline on the back of the neck
- Webbed neck
- Low-set ears
- Soft nails that turn up at the ends
- Multiple small, brown moles
- Lazy eye
- Osteoporosis (thin or weak bones) later in life
- Kidney problems
- Diabetes
- Heart problems
- High blood pressure

## Living with TS

TS cannot be cured, but there are ways to help with many of the symptoms. Some girls with TS may have heart problems and may need to have their heart checked each year. Additionally, some TS patients may need surgery for kidney problems, and blood pressure must be checked regularly. Many TS patients may have diabetes and need their health care providers to monitor their blood sugar. Thyroid disorders may also occur.

# Commitment to the GHD Community



## Pfizer Patient Affairs Liaisons

Pfizer Patient Affairs Liaisons are a team of nonsales, nonpromotional, field-based professionals. Pfizer Patient Affairs Liaisons are dedicated to serving the rare disease community by connecting patients and caregivers with Pfizer Rare Disease tools, including:

- Educational resources
- Access support
- Community events in your area

**A Pfizer Patient Affairs Liaison can be reached at [PfizerPAL.com](https://www.pfizerpal.com).**

## Additional resources

If you would like more information about GHD, you can contact your health care provider or the organizations listed below.

**Human Growth Foundation: [www.hgfound.org](https://www.hgfound.org)**

**The MAGIC Foundation: [www.magicfoundation.org](https://www.magicfoundation.org)**

**Turner Syndrome Society: [www.turnersyndrome.org](https://www.turnersyndrome.org)**

**Prader-Willi Syndrome Association: [www.pwsausa.org](https://www.pwsausa.org)**

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