Hormone Health NETWORK
Keep your body in balance

Acromegaly

WHAT IS ACROMEGALY?

Acromegaly is a rare but serious condition caused by too much growth hormone (GH) in the blood. GH is released into the bloodstream by the pituitary gland, located at the base of the brain. The blood carries GH to other parts of the body where it has specific effects. In children, GH stimulates growth and development. In adults, GH affects energy levels, muscle strength, bone health, and one's sense of well-being.

Too much GH in children is called gigantism and is extremely rare. Acromegaly in adults occurs mainly in middle-aged men and women.

DID YOU KNOW?

Acromegaly is a very rare condition. Each year, about three new cases of acromegaly occur for every million people.

WHAT CAUSES ACROMEGALY?

Acromegaly is usually caused by a non-cancerous tumor in the pituitary gland called a pituitary adenoma. The tumor produces too much GH and raises the level of GH in the blood. Too much GH also raises the level of insulin-like growth factor-1 (IGF-1), a hormone produced in the liver that also promotes growth. Rarely, acromegaly is caused by hormone-producing tumors in other parts of the body.

HOW IS ACROMEGALY DIAGNOSED?

If acromegaly is suspected, your doctor will do a blood test to check your level of IGF-1. High IGF-1 levels can mean that your levels of GH are also high.

Another way to diagnose acromegaly is with an oral glucose tolerance test. In this test, GH levels in the blood are measured after you drink sugar water. Normally, the sugar water will make the pituitary gland stop producing GH and blood levels drop. However, a GH-producing pituitary tumor will not stop making GH, so the levels of GH in the blood will not change.

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WHAT ARE THE SIGNS AND SYMPTOMS OF ACROMEGALY?

A person with acromegaly usually has large hands and feet, thick lips, coarse facial features, a jutting forehead and jaw, and widely spaced teeth. Often people with acromegaly sweat a lot.

Other signs and symptoms fall into three categories, depending on the underlying causes. Symptoms can be caused by high GH levels, hypopituitarism (pituitary hormone deficiency caused by tumor damage to the pituitary), or by tumor volume effects (when the tumor is large enough to compress surrounding brain structures).

SIGNS AND SYMPTOMS OF ACROMEGALY

Caused by high GH levels:

- Numbness or burning of the hands or feet
- Carpal tunnel syndrome
- High blood glucose (sugar)
- Heart failure or enlarged heart
- High blood pressure (hypertension)
- Arthritis
- Goiter (enlarged thyroid gland)
- Sleep apnea (breathing repeatedly stops and starts during sleep)
- Tiredness

Caused by hypopituitarism:

- Menstrual disorders (irregular bleeding; absence of periods)
- Lower sexual desire
- Tiredness

Caused by tumor volume:

- Headaches
- Vision problems (tunnel vision; vision loss)

HOW IS ACROMEGALY TREATED?

Acromegaly requires expert care. Too much GH and IGF-1 in the blood lower both your quality of life and how long you might live. The main goal of treatment is to lower GH and IGF-1 levels to normal. Treatment may be surgery, pituitary irradiation (radiation therapy on the pituitary gland), medication, or a combination of these options.

If the cause of acromegaly is a pituitary tumor, surgery to remove the tumor is the first treatment. Complete removal of some tumors is difficult and other types of therapy are often needed to reach normal GH and IGF-1 levels. If your GH level isn't normal after surgery, or if you aren't a candidate for surgery, then pituitary irradiation and medication are also options.

Irradiation can take a long time to bring GH levels down to normal. It may even take 10 to 20 years to be fully effective. Once the goal is reached, however, the effects of irradiation are permanent.

Drugs are also available to treat acromegaly, but they are not a cure. If surgery or radiation does not lower your GH levels, you'll probably have to take medication for the rest of your life. (Rarely, when medications are stopped, control of the disease continues.) The most effective medications for acromegaly are somatostatin analogs and a GH receptor antagonist. Another type of medication (dopamine agonists) works for some but not most patients. Some patients may benefit from a combination of these medicines.

Questions to ask your doctor

- **What are my treatment options?**
- **What are the advantages and disadvantages of each of my treatment options?**
- **Should I see an endocrinologist for my condition?**
- **How often should I have checkups?**
- **What else can I do to stay healthy?**

RESOURCES

- Find-an-Endocrinologist: *www.hormone.org* or call *1-800-HORMONE (1-800-467-6663)*
- MedlinePlus (National Institutes of Health), Growth Disorders: *www.nlm.nih.gov/medlineplus/growthdisorders.html*
- National Endocrine and Metabolic Diseases Information Service (National Institutes of Health): *endocrine.niddk.nih.gov/pubs/acro/acro.aspx*
- Mayo Clinic: *www.mayoclinic.com/health/acromegaly/DS00478*
- UpToDate.com, Patient information: Acromegaly: *www.uptodate.com/contents/patient-information-acromegaly*
- Human Growth Foundation: *www.hgfound.org*
- The Magic Foundation: *www.magicfoundation.org*

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The Hormone Health Network offers free, online resources based on the most advanced clinical and scientific knowledge from The Endocrine Society (*www.endo-society.org*). The Network's goal is to move patients from educated to engaged, from informed to active partners in their health care. This fact sheet is also available in Spanish at *www.hormone.org/Spanish*.

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