Symptoms of acromegaly

Patients with acromegaly typically have enlarged hands and feet, swollen lips, hardened facial features, a forehead and jaw that protrude forward, and spaced teeth. Other symptoms may include:

- Excessive sweating
- Headaches
- Vision problems
- Tiredness
- Arthritis
- Sleep apnea
- Numbness or weakness
- Skin thickening
- Skin tags
- Menstrual disorders
- Loss sexual desire
- High blood pressure

Treatment for acromegaly

The goal of treatment is to lower GH and IGF-1 levels to normal.

Treatment may include:

1) **Surgery:** Surgery to remove the tumor is the first treatment. *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.*
2) **Pituitary irradiation** (radiation therapy on the pituitary gland)
3) **Medication**: The most effective medications for acromegaly are *somatostatin analogs* and a *GH receptor antagonist*. Another type of medication (*dopamine agonists*) works for some patients.

ACROMEGALY

WHERE DO I GO FROM HERE?

St. Paul's Hospital and Vancouver General Hospital's Neuropituitary Program

Vancouver, British Columbia

"Acromegaly: The Sleeping Giant Within"
(www.acromegalysupport.ca)

Supported by an educational grant from:
EMD Serono

Contact Information

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Also ask us for these materials:

- The Acromegaly DVD
- Acromegaly Record Book
- Medication Guidelines & coverage
- Adrenal insufficiency book
- Acromegaly lab tests
- Transsphenoidal Surgery
- Endocrine links & support groups
- Travel letter

Adapted from:
Hormones & You: Acromegaly. **The Hormone Foundation.**
www.hormone.org

Acromegaly and You

What is acromegaly?

Acromegaly is a rare but serious condition caused by too much growth hormone (GH) in the blood. The pituitary gland in the brain is responsible for releasing GH into the bloodstream. GH is important for stimulating growth and development in children and affects energy levels, muscle strength, bone health, and a sense of well-being in adults. Acromegaly in adults is typically seen in middle-aged men and women.

Statistics show that there are about three new cases of acromegaly each year out of a million people.

What causes acromegaly?

Pituitary Adenoma

A **non-cancerous** tumour in the pituitary gland is called a pituitary *adenoma*. This tumour produces too much GH which raises the level of GH in the blood.

Excessive GH causes the level of *insulin-like growth factor-1* (IGF-1), a hormone produced in the liver that affects growth, to also rise.

How is acromegaly diagnosed?

A blood test to check your level of IGF-1 is done if acromegaly is suspected. Acromegaly is confirmed if the IGF-1 is well above the normal range.

Another test is the *oral glucose tolerance test*. Your levels of GH in the blood are measured at 0, 1, and 2 hrs after you drink sugar water. Normally, the pituitary gland stops producing GH in the presence of sugar water. If there is a GH-producing pituitary tumour, the pituitary will *not* stop making GH, and the levels of GH in the blood will not change.

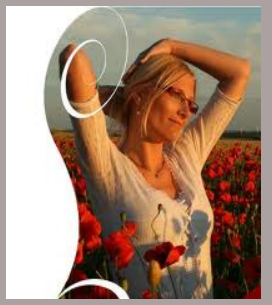
Other Tests: Sometimes after treatments for acromegaly such as surgery and/or radiation treatment, the body becomes deficient in hormones other than GH such as thyroid, prolactin, cortisol, testosterone and/or estradiol. These hormones must be monitored regularly

Imaging: MRI and CT scans are also done to help locate the pituitary tumour.

Other Resources

- www.hormone.org or call 1-800-467-6663
- The Endocrine Society (www.endosociety.org)
- True-2-me.ca
- http://www.cnetscanada.org/index.html (Neuroendocrine tumour society Canada)
- www.acromegaly.org (The Pituitary Tumor Network Association)
- www.rarediseases.org (National Organization for Rare Disorders)
- www.acromegalysupport.org (The Acromegaly Outreach Program)
- www.pituitary.org.uk (The Pituitary Foundation)
- www.pituitarydisorder.net
- www.pituitarysociety.org

You are not alone with your acromegaly



"Perfection is boring. If a face doesn't have mistakes, it's nothing"— quote from patient with acromegaly