Let's Talk About Acromegaly

What is acromegaly and what causes it?
Acromegaly is an uncommon condition that occurs when the pituitary gland produces too much growth hormone. The most common cause is a non-cancerous (benign) tumor in the pituitary gland (known as pituitary adenoma). However, in some cases, excess growth hormone can be produced by tumor located elsewhere in the body, such as the lungs, adrenal glands, and the pancreas. The condition develops very slowly over several years so that the physical changes are not noticeable straight away, but over several years, physical appearance will vastly change.

Is acromegaly inherited?
In general this tumor is not inherited. However, recent research has shown a small number of families in which acromegaly has been inherited. This inherited form of acromegaly is called 'familial isolated pituitary adenoma'. Someone with this gene is more likely to develop the pituitary tumor and release excess growth hormone when they are teenagers. They are likely to grow very tall because excess growth hormone is produced when the bones are still growing.

What are the signs and symptoms of acromegaly?
Several changes can occur over many years in both the physical appearance and other characteristics. These include:

- Bigger hands and feet
- Bigger jaw bone
- More prominent forehead
- Larger tone
- Excessive sweating
- Joint pain
- Headache
- Problems with vision
- Tiredness
- Weight gain

If acromegaly is not treated what can happen?
Complications can occur if acromegaly is not treated. Some of these complications can have major detrimental affects on health and can result in premature death. They include:

- High blood pressure (hypertension)
- Heart disease
- Arthritis
- Diabetes
- Kidney failure
- Polyps on the lining of your colon
- Sleep apnea
- Carpal tunnel syndrome
- Reduced secretion of other pituitary hormones (hypopituitarism)
- Uterine fibroids, benign tumors in the uterus
- Spinal cord compression
- Vision loss

Let's Talk About Acromegaly *(continued)*

How will my doctor know if I definitely have acromegaly?

To diagnose acromegaly, your doctor will perform a thorough medical history, physical exam and a combination of tests. These tests are usually done in the following steps:

1. Your doctor will take a blood sample to measure your levels of growth hormone (GH) and insulin-like growth hormone (IGF)-I. Elevated levels of these hormones suggest acromegaly.
2. Next, your doctor will do an OGTT (or oral glucose tolerance test). Normally, sugar in your blood causes GH level to fall. If you have acromegaly, your GH level will stay high.
3. Finally, your doctor may recommend an imaging procedure, such as magnetic resonance imaging (MRI), to help pinpoint the location and size of a pituitary tumor. If no tumor is found, other tumors may be looked at that might be responsible for high levels of GH.

If acromegaly is diagnosed, what are my treatment options?

There are a number of ways acromegaly can be treated, and the choice of treatment depends on the location of the tumor, you age and medical history. The different treatment options include:

Surgery. The goal is to remove the pituitary tumor to stop the GH over production and relieve pressure in the surrounding tissues. However, GH levels sometimes do not return to normal and further treatment involving medication may be required.

Radiation therapy. Radiation is mainly used after surgery if some of the tumor cells remain. Radiation can also be used as the main treatment, or used in conjunction with medication to help lower the GH levels.

Medication. Medication is used if surgery is considered too high risk or impossible due to the location of the tumor. The goal is to stop the rapid growth brought on by the increased GH levels. The different types of medication include somatostatin analogues (SSAs), dopamine agonists, and growth hormone receptor antagonists (GHRAs).

Where can I get more information or support?

There are several sources of information and patient support groups. Some of these are listed.

About acromegaly

http://www.aboutacromegaly.com/acromegaly-resources/support-groups-and-resources.jsp

The information is designed to provide you with valuable resources about acromegaly, from the first possible signs to diagnosis and disease management.

Acromegaly support and Outreach

http://www.somavert.com/tools/acromegly-support-and-outreach.aspx

If you or someone you care for has acromegaly, there are several groups listed that may help.

Acromegaly Support Group http://www.mdjunction.com/acromegaly

A community of patients, family members and friends dedicated to dealing with acromegaly, together.