ACROMEGALY

Patient Information Fact Sheet

What is acromegaly?

Acromegaly is a disease of the pituitary gland (a small gland found at the base of your brain) that causes too much growth hormone (somatotropin) to be produced. This can occur if there is a disorder of the gland, such as a tumor. If a pituitary tumor occurs during childhood, it will cause gigantism because of rapid overgrowth of the bones of the arms and legs. If a pituitary tumor occurs after adolescence when the bones have stopped growing, it will cause acromegaly, resulting in enlargement of the head, feet and hands. If childhood gigantism is not treated, it will lead to acromegaly in later life.

Acromegaly is a very rare disease, with around 117 new cases per million per year. It usually develops in adults between the ages of 30 and 50.

What are the symptoms of acromegaly?

Sometimes, the first symptoms of acromegaly are tiredness and sleep disturbance. There is no increase in height in acromegaly, but thickening of the bones causes enlargement of the head, and in particular the lower jaw. In addition, the hands and feet widen and the fingers become much broader. Increased cartilage growth can increase the size of the nose and ears, while increased cartilage growth in the chest can result in an increased chest girth. Overgrowth of the larynx (voice box) may cause the voice to deepen and the skin may become thicker and coarser in texture. Perspiration may also be a problem, especially in women, and the skin may become oily. Growth of a pituitary tumor increases pressure within the skull and can cause headaches and visual disturbances. In addition, around a third of people with acromegaly go on to develop diabetes.

The pituitary gland produces other hormones besides growth hormone, including thyroid stimulating hormone (TSH), follicle stimulating hormone (FSH) and adrenocorticotropic hormone (ACTH). In people with acromegaly, the rest of the pituitary gland may become underactive, resulting in decreased levels of these hormones. This can cause symptoms such as diminished sexual function, loss of menstrual periods (amenorrhea), and symptoms of an underactive thyroid gland. A pituitary problem diagnosed based upon these symptoms before the symptoms of acromegaly are apparent.

What tests confirm a diagnosis of acromegaly?

If your doctor thinks you may have acromegaly, you will be referred to a specialist, such as an endocrinologist. The specialist will give you a sugary drink and will then monitor the levels of sugar and growth hormone in your blood over the next two to three hours. If your growth hormone levels remain high throughout the test, then you have acromegaly. Physicians can also measure insulin-like growth factor I (IGF-I) levels, a protein which increase as growth hormone levels increase in people with suspected acromegaly. Elevated IGF-I levels almost always indicate acromegaly. However, a pregnant woman's IGF-I levels are two to three times higher than normal. Also, IGF-I levels decline with age and may be abnormally low in people will poorly controlled diabetes or liver or kidney disease. If the test for acromegaly is positive, an MRI scan of the pituitary is done to locate and detect the size of the tumor.

How is acromegaly treated?

Surgical removal of the pituitary gland is the first line option and may be necessary if it is large and is causing increasing hormonal problems. Alternatively, radiotherapy may be used to destroy the part of the pituitary gland that is causing the problem.

In some cases, drug treatment may be prescribed to regulate the release of growth hormone. Drugs used to treat acromegaly include **lanreotide** (Somatuline Depot) and **octreotide** (Sandostatin and Sandostatin LAR). These drugs are given by injection. For short-term treatment, before surgery or radiation therapy, octreotide (as Sandostatin) needs to be given three times a day. For long-term treatment, injections of lanreotide or octreotide (as Sandostatin LAR) may be given at intervals of one to four weeks. **Pegvisomant** (Somavert) is another injectable drug that may be used if other treatments are ineffective or are not tolerated. Recent studies suggest that pegvisomant may be useful in patients with glucose intolerance or overt type 2 diabetes. **Bromocriptine** (eg, Parlodel), a dopamine agonist, is another drug that is sometimes used to treat acromegaly. It suppresses the release of the hormone prolactin and can also reduce levels of growth hormone. It is given in tablet form. More recent studies suggest that **cabergoline**, a more selective dopamine agonist, may be effective in a larger number patients.

Further information

Acromegaly.org: www.acromegaly.org
National Institutes of Health: http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001364/
National Endocrine and Metabolic Diseases Information Service: http://endocrine.niddk.nih.gov/pubs/acro/acro.aspx
American Association of Clinical Endocrinologist: https://www.aace.com/files/acromegaly-guidelines.pdf

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