ACROMEGALY FACT SHEET

Acromegaly is a chronic hormonal disorder that occurs when excess growth hormone (GH) is produced. The majority of acromegaly cases are caused by a benign tumor in the pituitary gland that secretes excess GH, which leads to elevated levels of insulin-like growth factor (IGF-1). These elevated levels of IGF-1 can cause physical changes, such as enlargement of hands, feet and internal organs, facial features, and put patients at risk for serious health complications and a high risk of mortality.

The benign tumors that cause acromegaly can be classified into two categories based on their size: microadenoma, a tumor less than 10 mm, and macroadenoma, a tumor more than 10 mm. The majority of acromegaly cases are caused by a macroadenoma.

Worldwide, the estimated annual prevalence of acromegaly is between 125 and 295 people per million and the estimated incidence is three to four people per million. Acromegaly most commonly presents in middle-aged men and women. This debilitating disease can be difficult to detect because it can develop gradually and/or individual symptoms may be mistaken for another medical condition. In fact, the average delay from disease onset to diagnosis for an acromegaly patient is six to 10 years.

Prognosis

Patients with acromegaly may suffer from changes to facial structure, such as enlargement of forehead and jaw with pronounced under/overbite, spreading teeth and enlarged tongue. Women with acromegaly may experience interrupted menstrual cycles and galactorrhea (lactation not associated with childbirth). More serious problems may include heart disease, hypertension, diabetes, arthritis and an increased risk of colon cancer. If left untreated, acromegaly can result in a two- to three-fold increased risk of death. Heart disease is responsible for approximately 60% of deaths among people with acromegaly.

Disease Management Guidelines

The goal of acromegaly management is to achieve biochemical control of the disease, as measured by GH and IGF-1 levels, as well as reduction in tumor volume and clinical manifestations.

Currently, managing acromegaly includes surgical removal of the tumor. Success rates for acromegaly patients with a microadenoma are approximately 85%; however, surgery is only curative in approximately 30% of acromegaly patients with a macroadenoma.

Clinical Manifestations*

- Headaches
- Visual field defects
- Enlargement of forehead and jaw with pronounced under/overbite, spreading teeth and enlarging tongue
- Interrupted menstrual cycle
- Galactorrhea (lactation not associated with childbirth)
- Oily skin and excessive sweating
- Heart enlargement
- Impaired glucose metabolism
- Enlargement of hands, feet and head
- Colon polyps
- Soft tissue thickening of the palms of the hands and the soles of the feet
- Carpal tunnel syndrome
- Tiredness, fatigue, depression
- Impotence, loss of libido
- Sleep apnea

Co-morbidities

- High blood pressure (hypertension) and heart disease
- Diabetes
- Colon cancer
- Arthritis

**All of these signs and symptoms are not always present*

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