Understanding Acromegaly

A chronic hormonal disorder that occurs when excess growth hormone (GH) is produced.

Five Things Patients Should Know About Acromegaly

Acromegaly is a difficult pituitary disorder to manage. However, there are ways for patients to take an active role in their disease management, including educating themselves and engaging in an open and honest relationship with their doctors and nurses. Patient knowledge and empowerment can help those living with rare diseases like acromegaly, for which there are limited patient resources, manage their conditions. Five key things every acromegaly patient should know about their disorder are:

1. **The signs and symptoms of acromegaly**

   Acromegaly 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 time to diagnosis for an acromegaly patient is four to 10 years.

   It's important to know the signs and symptoms of acromegaly, which include enlargement of the hands, feet, facial features and internal organs, headaches, visual field defects and excessive sweating, among others. Serious health complications can also occur as a result of acromegaly when untreated or uncontrolled, including heart disease, hypertension, diabetes, colon cancer and arthritis.

   Patients should speak with their doctor about acromegaly if they have similar signs and symptoms, what it may mean when certain signs and symptoms worsen and the long term risk associated with the disease when improperly managed.

2. **Who treats acromegaly**

   Patients with acromegaly are typically managed by an endocrinologist, who should be their primary doctor, as well as a variety of healthcare providers, including diabetologists, cardiologists, surgeons, psychiatrists, nurses, primary care physicians, dentists, neurosurgeons, infectious disease specialists, orthopedists and other specialists who help manage the associated clinical manifestations or co-morbidities.

   It's important that patients take an active role in managing their acromegaly by establishing an open dialogue with their team of healthcare providers. It's critical for patients to always provide accurate information, including details on severity and changes in symptoms. Patients should also ensure they are making and keeping regular appointments, asking all questions that arise concerning their disease and management of their health, and that they keep track of symptoms and test results.

3. **What treatment options are available for acromegaly**
   There are several disease management options for acromegaly patients, including surgery, medical therapy and radiation therapy.

   - **Surgery:** Considered first-line therapy for most patients with acromegaly, transsphenoidal surgery is used to remove the pituitary tumor, which – when successful – normalizes growth hormone (GH) and insulin-like growth factor-1 (IGF-1) levels, two biochemical markers used to determine biochemical control of the disease, and reduces associated symptoms. In this type of surgery, the surgeon reaches the pituitary through the nose (transnasal) or through an incision in the upper lip (translabial) and is often able to remove the tumor, relieving pressure and immediately reducing GH levels.
   - **Medical Therapy:** There are different medical therapies used to treat acromegaly. In most patients, medical therapies are used after surgery in patients who have persistent disease. Medical therapies may also be used in patients who have minimal chance of cure from surgery, in patients who are poor surgical candidates or in patients who prefer medical treatment. Patients should speak with their healthcare provider to discuss how these therapies work and obtain more information.
   - **Radiation Therapy:** Radiation is most commonly used following surgery in cases where some tumor is still present and medications are not working; however, the full effect of this therapy may not occur for many years.

   Because everyone responds to treatment differently, it is important that patients work with their healthcare provider to determine which treatment option is best for them. Unfortunately, these treatments don't always work for all patients. Research is ongoing to address the needs of these patients.

4. **The importance of biochemical markers in acromegaly**
   Biochemical markers, sometimes referred to as biomarkers, are molecules found in certain parts of the body, including bodily fluids such as blood, urine and saliva. They can be measured to determine normal or abnormal biological function and help to identify the presence of a disease or condition. In acromegaly, the biochemical markers GH and IGF-1 play an important role in diagnosing patients and monitoring the status of their disease. Patients who are being treated for acromegaly should work with their healthcare providers to test their GH and IGF-1 levels and ensure they are within normal limits, which is an indication that the disorder is under control.

   Tests used to measure GH and IGF-1 in acromegaly patients include, but are not limited to:

   - **Oral Glucose Tolerance Test (OGTT):** For almost 40 years, the OGTT has been a standard measurement of GH in acromegaly. OGTTs are used to diagnose acromegaly and to measure biochemical markers in patients only after surgery. Following ingestion of a glucose drink, GH

levels in normal patients should be suppressed, but in patients with acromegaly, oral glucose does not suppress GH.

- **Random GH Test**: GH tests are used to help identify excess or diminished GH production and give the doctor information about the severity of a person's condition. GH can also be measured to assess the success of therapy for acromegaly. GH levels vary naturally depending on factors such as age, the time of day and time of last meal. To account for the variation in GH levels, a doctor may average the values from a series of “random” blood tests.

- **Serum IGF-1:** Serum IGF-1 is a test that measures the levels of IGF-1 in the blood. Because IGF-1 is released more evenly than GH, the serum IGF-1 test can be conducted at any time of day without fasting. This is also the ideal test for diagnosis since the absence of elevated IGF-1 levels in acromegaly is rare.

5. Where to find support

Patients with acromegaly may feel isolated and have difficulty obtaining information about their condition due to the rarity of the disease. However, they should know that they are not alone and information does exist.

Joining an acromegaly support group can help patients interact with people who are going through similar experiences. They provide a way for patients and families to talk with one another and share feelings and resources.
Patients can also learn more about managing and living with acromegaly by visiting websites like www.AboutAcromegaly.com. Other patient resources include The Hormone Foundation (www.hormone.org), National Organization for Rare Disorders (www.rarediseases.org) and The Pituitary Network Association (www.pituitary.org).

Patients should remember that their healthcare provider is their first source of information because he or she is equipped to accurately answer questions as it relates to the patient’s individual medical needs.

# # #