



# UNDERSTANDING **ACROMEGALY**

What You  
Need to Know



**RECORDATI  
RARE DISEASES**

GROUP

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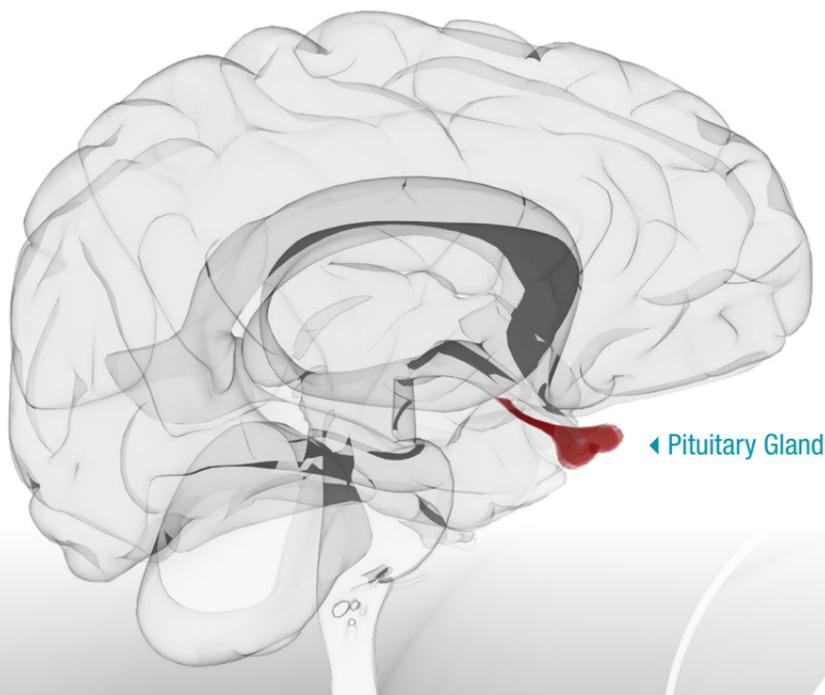
# INTRODUCTION

By now you know you have been diagnosed with acromegaly. This rare condition is generally caused by a noncancerous tumor on the pituitary gland that is located at the base of the brain. The tumor causes the pituitary gland to release too much growth hormone (GH). In turn, overproduction of GH causes the liver and other tissues to produce and release too much of the hormone insulin-like growth factor 1 (IGF-1). This hormonal imbalance leads to the symptoms associated with acromegaly.

For many people with acromegaly, surgery to remove the tumor is the first step in treatment.

However, some people cannot or do not want to have surgery. And even for those who choose this option, surgery does not always achieve the desired or lasting results. For those individuals, drug therapy may be an appropriate choice.

*See the section called “Treating Acromegaly” on page 6 of this brochure to learn more about surgery as a treatment.*



## Acromegaly Is a Rare Disease

Acromegaly affects an estimated 78 people per million. Acromegaly affects men and women equally, but becomes more common with increasing age.



## Acromegaly Is Caused by Prolonged Overproduction of Growth Hormone

GH is a hormone that controls the physical growth of the body. The process of producing GH begins in the hypothalamus, the part of the brain that makes other hormones that stimulate the pituitary gland to produce GH.

When the pituitary gland releases GH into the bloodstream, the liver produces IGF-1, which is the hormone that actually causes the growth of tissues in the body.

The hypothalamus also makes a hormone called somatostatin that slows or stops the production and release of GH. But when the production of GH by the pituitary gland is not slowed or stopped, IGF-1 levels continue to rise, leading to overgrowth of bones and enlargement of organs. Too much IGF-1 also changes how the body processes, stores, and uses sugars and fats that are known to lead to diabetes, high blood pressure, and heart disease.

*A noncancerous or benign tumor called an adenoma in the pituitary gland is what causes the overproduction of GH in more than 95% of people with acromegaly.*

## Symptoms of Acromegaly

The word acromegaly comes from the Greek words “acro,” meaning extremities, and “megaly,” meaning enlargement. One of the most common symptoms of the condition is, in fact, abnormal growth of the hands and feet.

With swelling of the hands and feet being an early symptom of the condition, people with acromegaly might notice that their rings or shoes have become too tight.

Over time, as the bones continue to grow, facial features begin to change, with the brow and lower jaw becoming more prominent, the bone of the nose becoming larger, and the teeth developing spaces between them.

Acromegaly can also lead to arthritis, carpal tunnel syndrome, and enlargement of the internal organs, including the heart.

### *Additional symptoms may include:*

- Joint aches
- Headaches
- Impaired vision
- Fatigue
- Weakness
- Thickening of the skin
- Oily skin
- Skin tags
- Enlargement of the lips, nose, and tongue
- Deepening of the voice
- Sleep apnea
- Excessive sweating
- Skin odor
- Abnormal menstrual cycles
- Breast discharge in women
- Erectile dysfunction in men
- Decreased libido

## Diagnosing Acromegaly

As you probably know, the road to diagnosing acromegaly can be a long and difficult one. The average length of time between the onset of first symptoms and reaching a diagnosis ranges from 4 to 10 years.

When acromegaly is suspected, the first step toward a diagnosis is for your doctor to run a few blood tests to measure your GH levels. A single blood test is usually not enough to diagnose acromegaly because GH is secreted by the pituitary gland in bursts, which means the amount of GH in the blood can vary greatly from minute to minute.

Doctors often use the oral glucose tolerance test to diagnose acromegaly because it is a highly reliable method. With the oral glucose tolerance test, you drink 75 to 100 grams of glucose solution. In healthy people, the drink will lower blood GH levels to nearly nothing (less than 1 nanogram per milliliter [ng/mL]), but in people who have too much GH, the levels of the hormone will not drop that low.

Doctors can also perform a blood test to measure IGF-1 levels in people with suspected acromegaly. IGF-1 levels are much more stable than GH levels over the course of the day and may be a more practical and reliable screening test, almost always indicating acromegaly.

Once blood testing of GH or IGF-1 has confirmed a diagnosis of acromegaly, magnetic resonance imaging (MRI) or computed tomography (CT) of the pituitary gland is used to locate and detect the size of the tumor causing GH overproduction.

## Treating Acromegaly

Surgery to remove the pituitary tumor is the treatment recommended for most people with acromegaly. While surgery is successful in many people, some people will see their levels of GH and IGF-1 remain too high even after surgery. In people whose acromegaly persists after surgery, additional treatment, such as medical therapy, is needed.

In addition, not all patients can or want to undergo surgery. For these patients, treatment with medication may be an appropriate option.

*Regardless of the treatment plan that you and your doctor go with, it is important to keep an open line of communication to help manage your treatment progress.*



## Committed to Advancing the Treatment of Rare Diseases

In the US, a rare disease is defined as a condition that affects fewer than 200,000 people.

**Recordati is committed to the research and development of treatments for rare diseases** and is one of the most active companies in the field.

While research and development efforts continue, Recordati Rare Diseases is here today to help patients and their physicians meet the challenges of diseases that have a significant impact on people's lives despite the small numbers of people those diseases affect. The company is **dedicated to partnering, discovering, and developing innovative products that improve the quality of life** and help people to enjoy longer, healthier, and more productive lives.



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## Online Resources for Additional Information

- Acromegaly Community
- Merck Manual Consumer Version

