

# Acromegaly Support

Volume 2, Winter 2004

## WELCOME

Acromegaly is a chronic disfiguring disease. The delay in making the diagnosis in most patients results in prolonged exposure to elevated levels of growth hormone (GH) and insulin like growth factor 1 (IGF-1). This is responsible for the signs, symptoms and comorbid conditions associated with Acromegaly.

In order for patients to understand their disease and have meaningful input into therapeutic decision making, they need education. Patient empowerment through education is a principle objective of the Acromegaly support network. We aim to provide this education and support through a network of services; internet, newsletters, support group meetings and patient symposia.

Our support group sessions/meetings are held monthly and attended by a variety of healthcare professionals to offer

management strategies for emotional health of patients, family and friends.

Our website, [acromegalysupport.org](http://acromegalysupport.org), will serve as an immediate resource for patients to find information on Acromegaly and therapeutic options. You can read patients' stories as they share their own experiences about living with Acromegaly. Dates and times of upcoming educational symposia, support groups and other local events are posted on the website. Because this program is part of a team approach with Cedars-Sinai Medical Center, NYU Medical Center and Massachusetts General Hospital, you will find details on current and future pituitary related events for each center.

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*"Patient empowerment through education is a principle objective .."*

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Quality of life for patients with Acromegaly is compromised on several levels. The function of this support network together with support group meetings is helping patients appreciate that they are not

alone and there is a very positive future to look forward to. We encourage you to reach out and attend one of our support groups as a beginning for you to take the step to find your balance by keeping yourself healthy on both a physical and emotional level or log on to our website for more information. Visit us at: [acromegalysupport.org](http://acromegalysupport.org).

We encourage you to attend one of our support groups to assist you in finding a balance for a healthy emotional well-being. Please log on to our website to get more information on our monthly sessions.

### MISSION STATEMENT

*We are committed to providing a reliable and authoritative comprehensive support network for people living with Acromegaly and their friends and family. Compassion, empathy, knowledge, experience and research is fundamental for treating all patients with dignity and respect. Our aim is to educate patients about their disease and empower them through knowledge and support.*

*Philip Barnett/Rosa Lopez*

## QUESTIONS & ANSWERS

**Q:** What are the co-morbid 'complications' of Acromegaly?

**A:** Conditions and diseases often associated with Acromegaly but generally not addressed under the headings of signs and symptoms of Acromegaly include:

- 1. cardiovascular
  - hypertension
  - heart enlargement
  - abnormal rhythms (arrhythmias)
  - heart failure
- 2. respiratory
  - sleep apnea
- 3. gastrointestinal:
  - colon polyps/cancer
- 4. metabolic
  - impaired glucose tolerance/type 2 diabetes
- 5. musculoskeletal
  - arthritis
  - jaw (mandible) dysfunction
- 6. renal
  - chronic kidney failure

This is not a comprehensive list of co-morbid conditions. However, it highlights those conditions that have the greatest impact on the health and quality of life of patients with Acromegaly. When treating patients with Acromegaly, physicians need to be aware of and manage these complications.

**Q:** What are the treatment options for Acromegaly?

**A:** The options are medical, surgical, radiotherapy and combinations of these.

Space does not permit a full discussion of the pros and cons of each therapeutic modality. These are addressed elsewhere in our newsletters and will be reviewed regularly:

### Medical:

Currently available FDA approved medications include:

1. Somatostatin receptor analogs (e.g. Octreotide, Lanreotide, Octreotide LAR) mimic the natural inhibitors of growth hormone (GH) secretion from GH secreting pituitary cells. These differ in their potency, duration of action and route of administration (subcutaneous, intramuscular).
2. GH receptor antagonist. This new class of agent is discussed further in "Recent FDA Approval of Somavert."
3. Dopamine agonists (Bromocriptine or Cabergoline) are more useful when the GH pituitary tumor secretes excess prolactin in addition to GH.

Medical therapy does not result in cure, but does reduce and normalize GH and insulin-like growth factor-1 (IGF-1) levels, produces some diminution in tumour size and promotes resolution of some of the complications of GH excess.

Agents from each of the three classes above may be used alone or in combination with agents from the other classes.

### Surgery:

Nowadays the routine surgical approach to GH secreting pituitary adenomas is via the transphenoidal route. Flexible or rigid scopes are advanced through the roof of the nose via the nostrils, and access the pituitary fossa through the sphenoid sinus which separates the roof of the nose from the cavity in which the pituitary is located (sella turcica). This approach together with new and improved instrumentation has had a

major impact on patient morbidity; less surgical complications, less patient discomfort, reduced hospital stay, quicker recovery time. Very large tumours may necessitate an approach from the front of the head (transfrontal), under the brain, to access the tumour that has enlarged significantly upwards out of the pituitary fossa.

Cure of Acromegaly following surgical resection of the pituitary adenoma depends on surgical expertise as well as the size and extent of 'spread' of the tumour.

### Radiation:

Several modalities of radiation are available, ranging from fractionated delivery over many days, to single episodes using a focused beam. Use of radiation treatment is generally as an adjunct to medical and/or surgical treatment. However, with newer technology, radiation treatment in certain instances as sole therapy is gaining acceptance.

Generally, lots of patients require combination therapy using all three of the options (medical, surgical, radiation) discussed above, either simultaneously or sequentially. Traditionally, surgical therapy has been the initial form of treatment for most patients with Acromegaly. There is a trend now amongst endocrinologists to recommend medical therapy as first line treatment for Acromegaly, especially where it is obvious that total removal of the tumour is impossible. At the present time, this is not accepted practice on a wide scale. Surgery is obviously necessary where sight is threatened or other complications are evident, due to the enlarging tumour mass. Surgical reduction of tumour bulk may be beneficial in patients due to have radiation treatment.

Watch this space for further discussion on the relative merits of each of the therapies discussed above.

*Philip Barnett, MD, Ph.D.*

## Recent FDA Approval of Somavert (Pegvisomant)

In April 2003, Somavert, a novel therapy for Acromegaly was FDA approved.

### Acromegaly, GH and IGF-1

Acromegaly is caused by a tumor of the pituitary gland that secretes excess growth hormone (GH) into the blood stream. The GH then attaches to special binding sites, called receptors, on the surface of the liver. When GH binds to these receptors, a series of reactions is triggered in the liver cell, which results in insulin-like growth factor-1 (IGF-1) being secreted by the liver. IGF-1 is responsible for several of the actions of GH in the body.

### Therapies of Acromegaly:

Current Acromegaly therapies include surgery, radiotherapy, Bromocriptine, Cabergoline, Octreotide, and Lanreotide. All act on the tumor to decrease GH secretion.

### How does Somavert work?

Somavert has a novel mechanism of action, in that it blocks the action of GH on the liver, resulting in reduced levels of IGF-1. Somavert does not decrease the amount of GH secreted by the pituitary tumor.

Somavert has a structure very similar to natural GH. The natural GH structure has been slightly altered, so that the resultant Somavert molecule is able to bind to the GH receptor more avidly than natural GH. When the Somavert molecule is bound to the GH receptor on the liver, the natural GH molecule is unable to bind to the receptor. The Somavert molecule is not able to stimulate synthesis of IGF-1, and thus the circulating IGF-1 level falls. As IGF-1 is responsible for many of the actions of GH, a decrease in IGF-1 level will lead to improvement in many of the symptoms of Acromegaly.

#### **How effective is Somavert?**

One hundred and twelve patients with Acromegaly received Somavert in a 12 week study. 91% of patients achieved a normal IGF-1 concentration.

#### **How is Somavert supplied?**

Somavert is supplied as a white powder which requires reconstitution with sterile water, in three different doses-10mg, 15mg, and 20mg. It is given as a subcutaneous (under the skin) injection once a day.

#### **What are the side-effects?**

A small number of patients experience redness at the injection site. Abnormalities in the liver function tests were reported in two patients. There is a theoretical risk that the pituitary tumor remnant may enlarge on Somavert. Long term surveillance studies are required to monitor effectiveness and side effects of this new therapeutic agent.

*Vivien-Herman Bonert, MD*

### ***Get involved in pituitary disease research!***

One of our primary goals at The Pituitary Center is to advance our understanding and knowledge of pituitary disease. We are committed to ongoing clinical research and invite you and your families to consider participating in the frontier of medical advancement.

## **CLINICAL STUDIES**

If you have a pituitary tumor and are interested in participating in a study which may lead to improved testing or treatment or may help prevent or cure pituitary tumors, please contact The Pituitary Center at 310-423-2830.

## **LOCAL NEWS LOS ANGELES**

Since Spring 2003, we have organized a number of activities and events for our patients. Starting this year, we now hold monthly sessions of our Pituitary Support Group meetings. We have tailored these to meet the needs and requests of our patients, addressing physical and emotional well-being. Dr. Margy Sperry, Psy.D, M.F.T. continues to facilitate our support group meetings. A Pituitary Center endocrinologist attends each session to discuss topics of interest and address medical questions. These sessions have successfully established a 'comfort zone' for our patients to find solace and support by sharing with others and expressing individual needs and concerns.

In February and March, Dr. Richard Chenik from the CSMC psychiatry department participated in our support group sessions. He spoke on various topics including 'emotional management' during moments of stress and anger, as well as helping patients and their caregivers understand and be understood by family and friends.

In May and July, we invited Ronit Roth, licensed yoga instructor, who shared her knowledge in the 'Healing Arts' by providing a tool for stress relief of mind and body. For the September session our guest April Numamoto, MA in Education directed an activity in Art Therapy. Patients, family members and friends were introduced to the relaxing benefits of art by painting terracotta pots and an ocean landscape.

Please call The Pituitary Center or log on to our website for more information on our Pituitary Support Group sessions.

**Rosa Lopez is the Medical Education Coordinator at the Pituitary Center. She heads patient support activities and can be contacted for more detailed information regarding these events at 310-423-3395.**

*June 1, 2003*

***"Acromegaly Patient Educational Symposium 2003"  
Shutters on the Beach, Santa Monica CA***

Our annual Acromegaly conference was a special patient-oriented event. The hotel setting was chosen especially to provide a relaxed and beautiful environment near the ocean. The day consisted of several educational and informative lectures on the subject of Acromegaly addressing the pathology, treatment options, new medications and therapies as well as information on available resources and patient support vehicles.

The faculty consisted of physicians from the CSMC Pituitary Center, Shlomo Melmed, MD "Latest Research", Vivien Bonert, MD "Acromegaly: What's Old & What's New?", Philip Barnett, MD, Ph.D. "Managing Acromegaly: Standards & Expectations", and Anthony Heaney, MD "Hormone Replacement Therapy". We also had fertility specialist, Christina Wang, MD, from Harbor UCLA deliver a lecture on "Fertility & Sexual Aspects of Acromegaly", and Margy Sperry, Psy.D, MFT "Emotional Well-Being."

During the lunch break, patients had an opportunity to sit and enjoy the delicious food as well as meet other patients, their family members and friends. Pituitary Center Physicians and staff had the opportunity as well to interact and enjoy the day on a more personal level with patients and their families.

### ***Save the Date***

**Pituitary Conference- March 2004  
Hotel Casa Del Mar, Santa Monica, CA**  
Invitations will be mailed to you.

**[acromegalysupport.org](http://www.acromegalysupport.org)**

Our patient support website has been officially launched. This resource for our patients and the general public will provide up to date information on Acromegaly in terms of education, finding information on appropriate treatment options and current and upcoming medications and therapies. Our website will also provide different arenas for emotional support of patients, family members and friends. In addition, we will post all current and future local events including support group meetings and conferences planned for Los Angeles, Boston and New York.

**Visit our website: [www.acromegalysupport.org](http://www.acromegalysupport.org)**

We are endocrinologists specializing in pituitary disease, specifically Acromegaly. As a group, we have extensive experience and expertise in the management of patients with Acromegaly and are involved in related research. Recognizing that patients needs, including updated information, psychological support, and awareness of treatment options are not always adequately addressed in the clinic setting, and through common interests, we have joined forces to establish this support network. Each center will present programs and meetings locally. These will be advertised on the website and in our newsletter.

Visit our website: [www.acromegalysupport.org](http://www.acromegalysupport.org)

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Disclaimer:

The information contained in this newsletter is for educational purposes only. It is not intended to be used to diagnose or to recommend treatment for Acromegaly. A physician consult should be obtained to address any medical concerns and to obtain medical treatment.

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