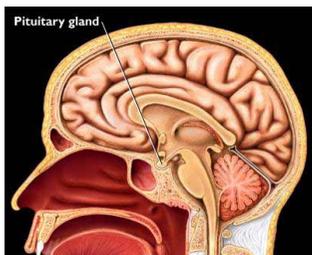


What is Acromegaly?

Acromegaly is a chronic metabolic disorder caused by the presence of too much growth hormone in the body. It results in gradual enlargement of body tissues including the bones of the face, jaw, hands, feet and skull.



Acromegaly is caused by a tumour (usually benign) on your pituitary gland also known as the 'master gland' as it controls many other hormone-making glands in the body.

Growth hormone is part of a cascade of hormones that, as the name implies, regulates the physical growth of the body until adulthood.

Secretion of growth hormone by the pituitary causes the production of another hormone called insulin-like growth factor (IGF-1) in the liver and it is this factor that actually causes the growth of bones and other tissues in the body.

Acromegaly accounts for a very small part of the population of those who are diagnosed with pituitary tumours, only approximately 4 people per million are diagnosed with Acromegaly per year.

Treatment of Acromegaly

In New Zealand, the treatment options are:

Trans-sphenoidal Surgery. - This is microsurgery, the tumour is removed via the nose and requires 24 hours in intensive care and a few days in hospital.

Stereotactic Radiotherapy - This option is available for those patients where the surgery may not have fully removed the tumour and growth hormone is still elevated or when surgery is not a safe option.

Drug Therapy - There are two medications usually trialled/prescribed. One is Cabergoline which is taken

Treatment of Acromegaly cont'd

orally and the other is a Sandostatin analogue. This is trialled for several days as a subcutaneous injection to test tolerance for the medication. Once this is established it is given as a monthly intramuscular injection

Replacement Therapy - 1 : 5 Acromegalacs will require some type of hormone replacement medication following surgery/radiotherapy, depending on any damage to the normal Pituitary gland during treatment.

This may involve tablets, hormone patches, injections or a nasal spray. The duration of therapy can vary from temporary replacement to permanent treatment.

Self Care

Knowledge - You have a medical condition, so ask questions, no question is a stupid question if it helps you understand what is happening to you.

Sleep – Sleep is the great rejuvenator for our bodies. If you are struggling with getting a good night's sleep tell your GP, your Endocrinologist, the nurses. etc.

Managing stress – Stress is good for us in small quantities. Write down what your stressors are and how you might manage them more positively.

Exercise – For those with arthritic joints, light exercise is good for those of able to do so.

Hobbies – Find something you enjoy doing and do it.

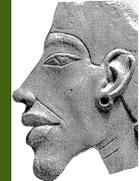
Relaxation – Learn how to relax, a quiet room, lie down or sit in chair and clear your thoughts and just be present, even just for a few minutes a day.

Talking about fears/concerns – A problem shared is a problem halved. This is one of the functions of the Acromegaly Support Group.

Talking to family about what is going on for you, they are not psychic, you need to tell them so they don't second-guess you and get it wrong.

Allow family to express their feelings - it is just as important for them to share, as they watch you going through the trauma of treatment, surgery, radiotherapy etc. and may, at times struggle with that.

The New Zealand Acromegaly Society



Aims of this group:

Acromegaly is such a rare disorder that patients and their families are often left feeling overwhelmed and isolated.

It was due to those feelings that Dr Catherine Chan (also diagnosed with Acromegaly) formed The New Zealand Acromegaly Society in November 2010.

At the inaugural meeting in February 2011, a steering group was formed from the 44 Acromegalacs and their families who attended from all over New Zealand.

The response to this support group has been tremendous and we are currently seeking registration as a charitable organisation.

The aim of this society is to link us together through peer support, education and regular social gatherings as defined below:

- To provide information and support to patients and their families
- To set up a patient & family contact register
- Organise social gatherings
- Organise educational seminars
- Regular Newsletters

Quality of life is the key to managing Acromegaly. Ask questions, search the net and be proactive in managing the impact of your condition!

Useful Links



Acromegaly Community

US based internet patient support group with patient forums

<http://acromegalycommunity.com>



Australian Pituitary Foundation

www.pituitary.asn.au



The Pituitary Foundation UK

www.pituitary.org.uk

Contact us:

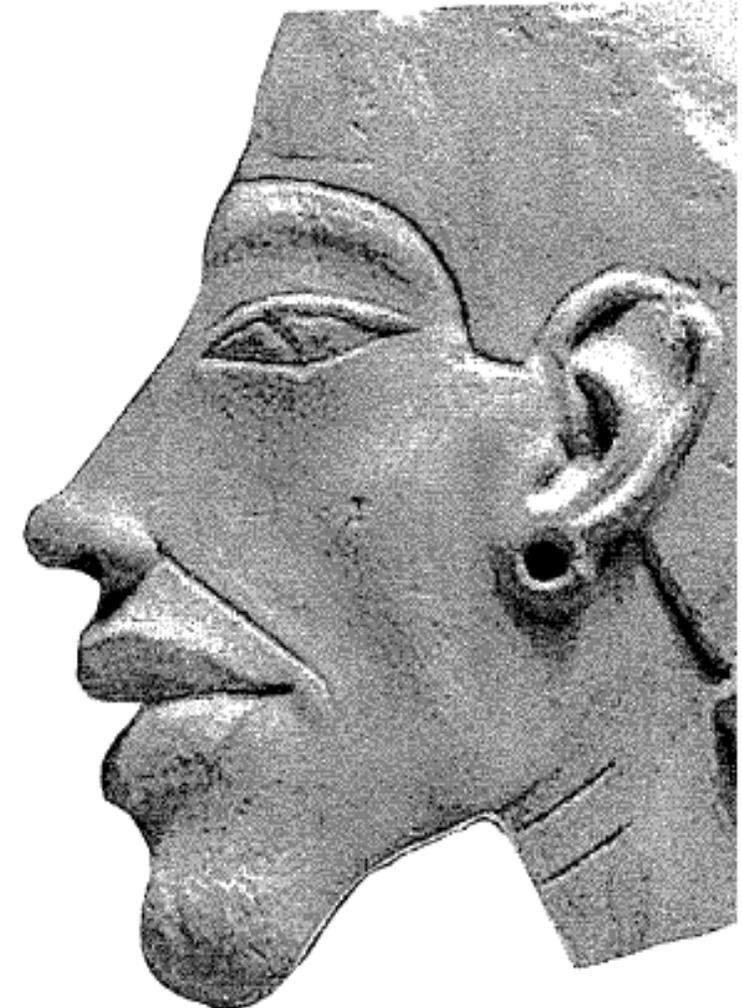
The New Zealand Acromegaly Society
c/- Secretary
PO Box 302
MORRINSVILLE 3340

www.acromegaly.org.nz
info@acromegaly.org.nz

The New Zealand Acromegaly Society



If you have been diagnosed with a growth hormone secreting pituitary tumour then you are in good company. Pharaoh Amenhotep IV known as "Akhenaton" is one of the earliest known persons thought to have been afflicted with Acromegaly



Ac-ro-meg-a-ly
"a-kro'me-g-le"

: chronically elevated growth hormone production marked by progressive enlargement of hands, feet and face.

Acro –meaning limbs of the body
megaly– meaning enlargement of