

The New Zealand  
Acromegaly Society

# Acromegaly

Supporting & Educating  
those affected by  
Acromegaly and their  
families



**INFORMATION BOOKLET SERIES**

## INTRODUCTION

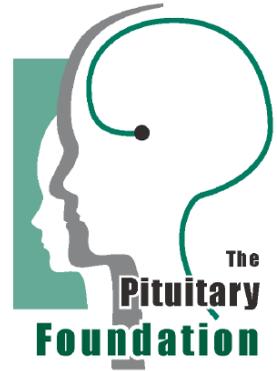
The New Zealand Acromegaly Society is a charitable organisation supporting patients with Acromegaly, and their families.

Website: [www.acromegaly.org.nz](http://www.acromegaly.org.nz)

Email: [info@acromegaly.org.nz](mailto:info@acromegaly.org.nz)

The aim of this leaflet is to provide general information about the condition Acromegaly. You may not find that all of the information applies to you in particular but we hope it helps you to understand your condition better and offers you a basis for discussion with your GP, Endocrinologist and Neurosurgeon.

A very special thank you to The UK Pituitary Foundation for allowing us to reproduce their Information Booklet and adapting it to the New Zealand's health system.



[www.pituitary.org.uk](http://www.pituitary.org.uk)

## MEDICAL ADVISORS

The New Zealand Acromegaly Society gratefully acknowledges the contributions from medical professionals to the development of this series of Information Booklets (listed in alphabetical order):

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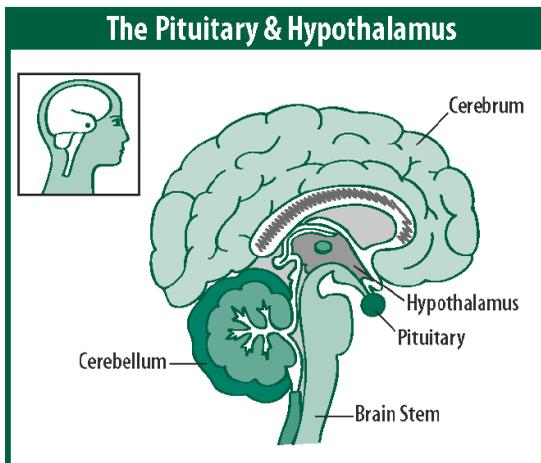
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## WHAT IS ACROMEGALY?

*The name "acromegaly" comes from the Greek words for "extremities" (acro), and "great" (megaly).*

Acromegaly is a hormonal disorder that results from too much Growth Hormone (GH) in the body. The pituitary, a small gland situated behind the bridge of your nose and at the base of the brain, makes GH. Acromegaly is caused by a benign (non-cancerous) tumour of the Pituitary Gland, which is called an adenoma and this produces too much GH.

Secretion of GH by the pituitary into the bloodstream stimulates the liver to produce another hormone called insulin-like growth factor 1 (IGF-1). IGF-1 is what actually causes tissue growth in the body. Growth hormone has effects on many different parts of the body; in adults it is important to maintain normal energy levels and to keep body tissues, such as muscle and bone, healthy. In children, of course, it is essential for normal growth.



Acromegaly usually develops in adults between the ages of 30 and 50, but symptoms can appear at any age. If acromegaly develops before you have stopped growing (which usually occurs between the ages of 15 to 17) it can cause Gigantism, where people are very tall, because GH promotes growth of the legs and arms. As the growth of bones stops after puberty, excessive GH in adults won't result in increased height, but may cause various other changes.

Acromegaly is a traditionally conditioned a rare condition with an incidence of 4 - 6 new cases per million of the population being diagnosed each year. Although recent studies show incidence maybe much higher. The diagnosis is often delayed as the symptoms develop gradually over time, and patients and families may not notice the changes. Patients may have had acromegaly for a number of years before the condition is recognised.

# WHAT ARE THE SYMPTOMS OF ACROMEGALY?

Early symptoms may include tiredness and swelling of the hands and feet. Patients may notice a change in finger ring or shoe size, and particularly the width of their feet. Gradually, bone changes alter the individual's facial features with the brow and lower jaw protruding. The nasal bone enlarges and teeth may become spaced out.

The overgrowth of bone and cartilage can lead to arthritis and when tissue thickens it may trap nerves, causing Carpal Tunnel Syndrome which results in weakness, numbness or pain in the hands. Organs in the body, such as the heart may enlarge.

## **Other symptoms of acromegaly can include:**

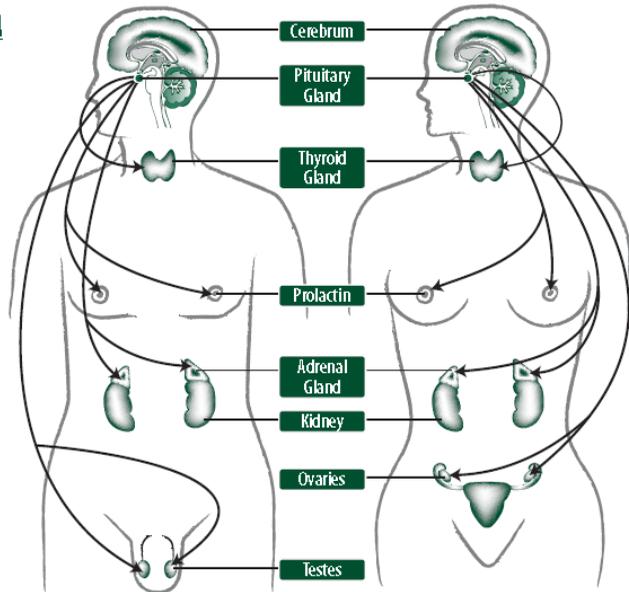
- Enlarged lips, nose and tongue
- Deepening of the voice due to enlarged vocal cords and sinuses
- Thicker, coarse, oily skin
- Joint aches
- Excessive sweating and skin odour
- Skin tags - tiny flesh-coloured finger-like projections on the skin
- Reduction, or lack of libido
- Erectile dysfunction in men
- Abnormalities of the menstrual cycle and sometimes breast discharge in women
- Headaches
- Fatigue and weakness
- Impaired vision & visual field
- Sleep apnoea - breaks in breathing during sleep due to obstruction of the airway
- High blood pressure
- Diabetes mellitus

Apart from the pituitary tumour causing problems by excessive GH production, the tumour can cause problems by pressing onto the normal pituitary gland, leading to inadequate hormone production by the remaining pituitary gland.

Your doctor will carry out blood tests to see if the other hormones produced by the pituitary gland are affected. These include:

- TSH Thyroid stimulating hormone – this stimulates the thyroid gland to produce T4 thyroxine & T3. Thyroxine controls many bodily functions including metabolism.
- PRL Prolactin – stimulates breast milk production during breastfeeding. It is however present in low levels at all times in both males & females.
- ACTH Adrenocorticotrophic hormone – this stimulates the adrenal glands to produce a hormone called cortisol. This is an important hormone and is essential to life (*see separate Information Booklet on Hydrocortisone*)

## THE ENDOCRINE SYSTEM



- ADH Antidiuretic hormone – is produced by the posterior pituitary and controls the kidneys to maintain water balance in the body. This hormone is important, if deficit and untreated can be life threatening.
- LH Luteinising hormone & FSH Follicle stimulating hormone – controls reproduction and sexual characteristics. In women they stimulate the ovaries to produce oestrogen and progesterone. In males they stimulate the testes to produce testosterone and sperm.

## HOW IS ACROMEGALY DIAGNOSED?

Once acromegaly is suspected, tests will be needed to confirm the diagnosis. You will probably not have all of the tests listed below, but you will have some of them. The details may vary from centre to centre, therefore you should always follow your doctor's instructions.

For all tests we recommend you request a copy of your results, and filing these in your own folder at home. This can be a valuable asset when visiting specialists who haven't seen you before, especially if you need to travel to another hospital or city for treatment.

### Blood Tests

If your doctor suspects acromegaly, the first tests you are likely to have are baseline blood tests. These will include standard blood tests plus tests for levels of pituitary hormones, such as cortisol, thyroid, prolactin and sex hormones.

For diagnosis of acromegaly the most important results are your GH (Growth Hormone) and IGF-1 (Insulin-like Growth Factor 1). IGF-1 is a protein which mediates the growth promoting actions of GH, hence high levels are a sign of excess GH activity.

The average level of GH is higher in acromegaly. However, a single blood test of an elevated GH level is not sufficient to diagnose acromegaly as GH is secreted by the pituitary in spurts and results can vary widely from minute to minute. Therefore IGF-1 is often used as a screening blood test as the level of IGF-1 is stable throughout the day, so it is a more reliable reflection of acromegaly for diagnostic purposes. IGF-1 will also be repeated over time to check your body's response to treatment.

As GH levels fluctuate throughout the day, a single high level does not necessarily mean something is wrong. A more accurate test for GH to be measured is by using a suppression test, known as an oral glucose tolerance test (OGTT). This test is usually done when there is some uncertainty as to whether the IGF-1 level is borderline abnormal. You must fast for 12 hours before the test. After the first blood sample is taken you will be given a glass of sweet glucose solution to drink, which in healthy people would lower GH levels, but in those with acromegaly this suppression of GH levels does not occur. Blood samples will then be taken on half hourly intervals for two hours, and are tested for GH and glucose levels (This can vary from centre to centre).

The glucose tolerance test is usually not a problem for most people. There is a small risk that you may experience nausea, or stomach ache due to not eating. Remember to tell the lab staff if you do not feel well. Remember to take a book (or something to occupy yourself with) along to the test as you will be sitting around for several hours!

## **MRI Imaging**

After acromegaly has been diagnosed by the above testing, a magnetic resonance imaging (MRI) scan of the pituitary is used to locate and detect the size of the tumour causing excessive GH production. MRI uses powerful magnet and radio waves, without the use of X-rays, and the procedure is safe and painless. It takes 30-60 minutes to take a full picture of your brain.

During the procedure, you lie down on the table and your whole body goes into the MRI machine, which some people can find claustrophobic. The MRI machine makes a lot of thumping noise and earplugs or music headphones are often available to help you manage this. If you are concerned please tell the radiology staff prior to your appointment, some centres will allow you to bring your own CD for you to listen to during the procedure.

Before the procedure you will be asked to change into a robe as it is very dangerous to have anything metal in the room due to the strong magnetic fields produced by the MRI machine, including any metal buttons, zips or jewellery. You

will be asked if you have a pacemaker or any metal implants (eg. Hip replacement).

Often a contrast solution (usually gadolinium) is injected intravenously during the scan to outline the tumour and differentiate it from normal pituitary tumour. The technicians will explain this to you prior to the procedure.

During the test the technicians can talk to you through a speaker, and there is usually a mirror enabling you to see the staff outside the room in the adjoining control booth. You will be asked to keep as still as possible to obtain a clear image, small movements like blinking or swallowing are okay.

The MRI is reviewed by a Radiologist (doctor specialising in Radiology), and a report may take up to a week before it is available. Usually an area of pituitary abnormality is seen on the MRI scan but occasionally the tumour is too small to be seen. Very rarely, if a brain scan completely fails to detect a pituitary growth, the doctor would look for an "ectopic" tumour that may cause GH production from elsewhere in the body.

### **Vision Field Tests**

Depending on the appearance of the tumour, a visual field test maybe carried out by an optometrist or ophthalmologist, to assess whether the tumour is causing any pressure on the optic nerve, as this nerve passes very close to the pituitary gland.

Other tests maybe carried out on an individualised basis.

## **HOW IS ACROMEGALY TREATED?**

Treatment options include surgery, medical therapy and radiotherapy. The goals of treatment are to:

- Reduce excess GH and IGF1 to normal levels
- Relieve any pressure that the growing tumour may be exerting
- Preserve normal pituitary function, or to treat any hormone deficiencies
- Improve the symptoms of acromegaly and prevent complications of the disorder from developing

Studies show that untreated acromegalic patients are more likely to suffer from diabetes, high blood pressure and heart problems with a reduced life expectancy compared to the normal population. These are improved after the successful treatment of acromegaly.

Acromegaly may be treated by surgery to the pituitary gland to remove or reduce the size of the tumour, by radiotherapy, by drug treatment, or a combination of these. The first treatment is surgery, although in some centres drug treatment to reduce the size of the tumour is given first. The aim of all treatments is to reduce GH and IGF-1 levels to normal, in order to improve the specific symptoms of acromegaly in addition to maintaining general well-being.

## Surgery

The operation is usually carried out by going through the nose. This is called Transsphenoidal Surgery. By going behind the nose like this, the surgeon can see your pituitary gland without having to operate on the main part of your head.

Most patients can be treated very successfully this way, although results are usually better if the tumour is small. The operation takes about an hour and a half. You will normally be in hospital for about five days. For the best results it is important to be referred to an experienced pituitary surgeon and your endocrinologist will be able to advise whom you should see. (Please see *our Information Booklet titled "Pituitary Surgery" for further details about the operation.*)

Surgery will normally lower your GH levels considerably, but in some instances the acromegaly is not cured. In such cases, consideration will be given to further treatment with drug therapy and/or radiotherapy.

## Drug Treatment

There are three types of drugs for treating acromegaly - each acts by a different mechanism:

1. **Somatostatin analogues** work on specialised molecules (somatostatin receptors located on the tumour) to inhibit GH release.
2. **Dopamine agonists**, which work on alternative cell surface regions (dopamine receptors) on the tumour to inhibit GH release by a different mechanism to octreotide.
3. **Pegvisomant**, a new drug which works by blocking the effects of GH (primarily by reducing the ability of GH to generate IGF-1) but doesn't actually reduce GH production.

**1) Somatostatin analogues** require administration by injections.

- **Octreotide** (brand name Sandostatin, manufactured by Novartis)
- **Lanreotide** (brand name Somatuline, manufactured by Ipsen)
- **Pasireotide** - given by monthly injection; this agent may act on additional receptor sites on the pituitary adenoma and suppress growth hormone more completely than octreotide.
- Lanreotide and Pasireotide are not marketed in NZ at present. Other types of somatostatin analogues are in development e.g. oral octreotide.

**Octreotide** can be given once a month deep into muscle (intramuscularly) for the long-acting preparation (Sandostatin LAR, Novartis). The long-acting preparation is usually given by a nurse at a hospital endocrine clinic or at your GP surgery. Occasionally more frequent injections are needed to control growth hormone levels.

A short acting version of octreotide is also available, which requires injection under the skin (subcutaneously) three times a day. A test dose of the short acting

version is often given to a patient before they are commenced on the long acting option, to ensure the patient can tolerate this medication.

Octreotide helps the symptoms of acromegaly by reducing growth hormone levels into the target range in more than half of patients. When you first start taking octreotide, it may give you stomach upset or diarrhoea, but these effects usually wear off within a few days. In the longer term it may cause gallstones, but this is rare.

**2) Dopamine agonists** - there are several types available, all are taken by mouth but only two are available in New Zealand:

- **Cabergoline** (brand name Dostinex, manufactured by Pfizer)
- **Bromocriptine**

Cabergoline is a newer long-acting dopamine agonist that causes fewer side-effects than bromocriptine, appears to be more effective in lowering GH and IGF-1 levels, and may only need to be taken once or twice weekly. It is not licensed for the treatment of acromegaly but is an accepted and widely used treatment. Dopamine agonists are used to treat many conditions other than acromegaly, and patients using dopamine agonists in very large doses (such as those with Parkinson's disease) occasionally develop heart valve problems. This has not clearly been shown to occur when patients use low doses (as used in Acromegaly), although this should be discussed with your endocrinologist. He/she may suggest regular heart scans (Echocardiograms) as a precaution especially if the required dose is high.

Bromocriptine usually needs to be taken two or three times a day, and is usually only used now if cabergoline is not tolerated.

Unfortunately, although dopamine agonists are taken by mouth, they are often less effective than somatostatin analogues which have to be injected. They may cause you to be constipated, although this can be alleviated by increasing the fibre in your diet. At the beginning of treatment, you may also suffer nausea or dizziness when you first stand up. These effects also tend to wear off with time.

**3) Pegvisomant** (brand name Somavert, manufactured by Pfizer) is a completely different way of treating acromegaly. All other current forms of treatment attempt to lower the amount of GH released by the pituitary gland. Pegvisomant is a blocker of the action of GH. It does not try to inhibit the release of GH from the pituitary into the blood but instead stops the GH having its usual action on cells throughout the body, and hence lowers blood IGF-1 levels.

This should block all the unwanted effects of GH and studies in patients with acromegaly suggest it is very effective. It is given as a daily subcutaneous (under the skin) injection. It is currently used for patients in whom the more traditional treatments have not been successful. At present pegvisomant is not available in New Zealand.

## Radiotherapy

Radiotherapy (treatment with radiation) might be needed if your surgery has not been completely successful (not all the tumour could be removed) and growth hormone remains sub-optimally controlled with drug therapy. The most common reason for incomplete tumour removal is proximity to the important blood vessel supplying the brain (e.g. internal carotid arteries), and the cranial nerves. In this situation the surgeon may decide that it is safer to leave some of the tumour behind and rely on other ways of lowering GH. If you are given radiotherapy, it will be planned and carried out with extreme care.

Improvements in pituitary scanning and computerised control of radiotherapy mean that new forms of finely focused, high dose stereotactic radiotherapy are available in some NZ centres.

*(Please see our Information Booklet titled "Radiotherapy" for further details.)*

## WHAT EFFECTS WILL I SEE FROM MY TREATMENT?

Once treatment is successful, you should notice that the soft tissue in your hands and feet decrease in size and patients often notice that their facial features gradually return towards normal. This may take some time, but do not despair - improvements will happen once treatment is successful.

If you were suffering from excess sweating this should decrease and if you had sugar diabetes, it should improve, or disappear altogether. Your headaches will usually improve and so should any visual disturbances that may have been present beforehand. If you snored, it should be improved. Any increase in bone thickness may revert slowly back to normal but you may need to prepare yourself for the possibility that this reversal could be incomplete.

## HOW IS MY PROGRESS MONITORED?

*All patients with acromegaly should be looked after by a specialist in this condition (an endocrinologist). Ideally your endocrinologist will have access to specialist nurses and radiology plus access to a neurosurgeon specialising in pituitary disease.*

The success of the treatment of your acromegaly needs to be monitored. The aim of treatment is to lower your average GH level to less than 1 ug/l and have your IGF-1 level in the normal range for your age.

Your endocrinologist will ask you how your symptoms have changed, in particular whether there has been any change in your finger ring size and facial appearance. It is also important for you to have regular blood tests to check your GH and IGF-1 levels, as well as the function of the rest of the pituitary gland. GH & IGF-1 can be measured as single blood samples or during a glucose tolerance test (see above).

## ACROMEGALY AFTERCARE

It is possible that your condition will require long-term monitoring with regular blood tests and this will often be shared by your Endocrinologist and GP. Because acromegaly is relatively rare, you may find that you are the only patient with this condition in your GP's surgery.

People with acromegaly have an increased chance of developing bowel polyps (small benign growths) and bowel cancer. You maybe be offered a baseline colonoscopy. A colonoscopy is a test where a doctor looks into your colon (large bowel) using a flexible telescope; this test can diagnose bowel problems and is carried out to ensure earliest detection, even before symptoms develop, so that the chance of a complete cure is high. However, always tell your doctor if you develop any new symptoms from your bowel, such as persistent diarrhoea, passing mucus, passing blood or abdominal pain.

NB. If you are taking hydrocortisone, it is important to tell the doctor before the colonoscopy procedure. You will need to double your usual dose of hydrocortisone the day before the procedure, when the bowel is cleaned out. Often a 100mg injection is given 30 minutes before the procedure by the doctor.

## COPING WITH THE STRESS OF ACROMEGALY

In addition to physical changes in acromegalics, many find their illness emotionally traumatic - particularly if they were unwell for some time before a correct diagnosis was made. There may be stress caused either by specific physical aspects (for example: loss of libido, exhaustion, joint pain) or by factors such as changes to your body, face and anxiety.

In addition, both the fear of anticipated surgery, so close to the brain and the fact that for some people recovery can take quite a while, can be stressful. All of these issues can be just as difficult for family and close friends as for the patients themselves.

Your GP will be able to arrange counselling if this is required. You may also find it useful to make contact with us for support:

[www.acromegaly.org.nz](http://www.acromegaly.org.nz)  
or email [info@acromegaly.org.nz](mailto:info@acromegaly.org.nz)

We can put you in touch with other people who are keen to help and support you, including other acromegaly sufferers or their family members.

There are new research emerging in recent years which has identified several psychosocial issues related to pituitary disease. These include: increased levels of depression, anxiety, appearance-related concerns, a reduced quality-of-life and well-being. These impact on diagnosis, treatment, and the realisation that the condition is frequently a long-term one.

# HOW WILL ACROMEGALY AFFECT MY LIFESTYLE?

## Employment

For your stay in hospital if you have had surgery, the ward staff will give you a certificate for your employer and advise you how long you will be expected to remain off work. Your GP can issue further certificates if you require these.

If you are experiencing any difficulties in retaining or returning to your employment, at any stage of your pituitary condition we suggest that you contact your local Citizens Advice Bureau (CAB) for the most up to date information about employment rights and where to get additional advice. [www.cab.org.nz](http://www.cab.org.nz)

If you need extra employment and financial assistance because of a disability contact your local Work and Income Centre [www.workandincome.govt.nz](http://www.workandincome.govt.nz)

## Driving

You should discuss with your GP or endocrinologist if there is any reason why you should not drive. Many patients with acromegaly will find there are no restrictions, but you should check with your GP or specialist.

The only condition likely to affect patients is having a problem with your eyesight. Transsphenoidal surgery does not in itself limit your entitlement to drive and your doctor or specialist will give you full advice.

You may also seek extra advice from the NZTA (New Zealand Transport Agency) by calling their contact centre on 0800 822 422.

## Insurance

Your health insurance provider will require medical reports and each case will be assessed individually to make any adjustments found to be necessary on your premiums. Company policies do vary widely and you may need to shop around. Don't be disheartened if the first response is disappointing.

## Medicalert®

If you are on hydrocortisone replacement therapy, it is a good idea for you to wear an emblem, such as a MedicAlert® bracelet or necklace, as the information on this will help doctors if you have an accident and are unconscious.

An application form can be obtained from the MedicAlert Foundation  
Freephone: 0800 840 111, [www.medicalert.co.nz](http://www.medicalert.co.nz)

We advise that you discuss this with your GP, who should be able to help you complete the application form.

## COMMON QUESTIONS

- **What happens if my octreotide has been left out of the fridge?**

The long acting preparation (Sandostatin LAR) can be left out of the fridge on the day of injection, provided it has been kept away from direct sunlight and excessive heat, for up to 24 hours. The injection kit can be re-refrigerated if needed.

The short acting subcutaneous preparation can be left out of the fridge for up to two weeks for day-to-day use. However you should keep them in the fridge as much as possible.

- **Is it safe to take other prescribed medicines alongside octreotide?**

Octreotide can interact with other medicines; make sure your doctor knows you are taking octreotide.

- **What should I do if I want to travel abroad?**

If you are on long-acting octreotide injection, it is often easiest to get an injection before your trip, and after your return. If you are going away for long trips, your endocrinologist maybe able to help you find a doctor or nurse overseas to give your octreotide injection (costs will apply), but you will need to take your sandostatin LAR injection kit with you.

If you will be travelling with medications, especially if you will be carrying needles and syringes, you will need to ask your doctor for a letter to say that you need to carry needles and syringes with you for medical purposes.

Always carry all your medications in your hand luggage.

- **How do I keep my octreotide cool during the journey?**

As mentioned earlier, it is not a problem if your octreotide is kept out of the fridge up to 24 hours. However, we advise keeping your supply in a cool bag whilst travelling, and take several ice packs with you. Your chemist should be able to assist you with this.

- **After I have injected my octreotide, I tend to get a stinging feeling and redness around the injection area for about 15 minutes. Can anything be done about this?**

If you take care to ensure your injection has reached room temperature before injecting, this effect should be minimised.

- **Can I drink alcohol?**

Moderate alcohol intake should not cause problems, but you should speak with your specialist or GP for advice.

## USEFUL ADDRESSES

### Patient Support Groups Worldwide:

- **The UK Pituitary Foundation** [www.pituitary.org.uk](http://www.pituitary.org.uk)
- **The Australian Pituitary Foundation** [www.pituitary.asn.au](http://www.pituitary.asn.au)
- **Acromegaly Community** [www.acromegalycommunity.com](http://www.acromegalycommunity.com)  
A US & internet based support group

## LIVING WITH ACROMEGALY – ONE PATIENT’S STORY

My acromegaly journey began in the mid-1980s although, in retrospect, I can see that it started some years earlier. I started to suffer a series of health problems which, at the time, did not appear to be connected. My shoe size had increased over about five years from size 9 to size 12 and I had to have my ring enlarged twice because my fingers had become larger and fleshier; indeed, my fingers had become so fleshy, I could no longer fold them flat against my palms.

Then I suffered pain in both knees, mild at first but growing in intensity until I was having difficulty in walking. My GP could find nothing wrong and the suggested I take more exercise. I remember joking that it was growing pains - little did I realise how close to the truth I was! The pain moved down into my shins before easing and finally disappearing. A few months later, a similar thing happened to my elbows but I decided not to bother my GP. The next area to be affected was my jaw, where I developed an ache just below my right ear and then one morning I awoke to find that I could barely open my mouth. My GP referred me to my dentist who, after examination and X-rays, said it was not a dental problem. Once again, my GP seemed at a loss to know the cause and over the next fortnight the pain slowly eased until I could open my mouth fully once again.

By early 1985, I knew there was something wrong with me. I had a general, indefinable feeling of "not being right" but nothing I could pinpoint or put a name to. My lips had become much fleshier and I was starting to have difficulty pronouncing some words. In June of 1985, I went to my GP for a medical relating to my driving licence. I passed this without any problem but, as I was leaving, my GP asked to look at my hands and feet again and asked various questions. He then dropped the bombshell by saying he would like me to attend the local hospital for some tests because he felt I might be suffering from something called acromegaly. I do not know whether he had recently read an article on acromegaly but, after all those months and visits, he had finally diagnosed my problem!

The hospital tests confirmed that I was acromegalic and the endocrinologist stressed that it was a rare condition and my GP had been very good in spotting it

- this went some way to alleviating my feelings towards my GP over all the dismissed aches and pains. The endocrinologist estimated, from a series of family photographs, that it had probably started around 1978/79 when I was about 27. My treatment began with a course of bromocriptine tablets to control and shrink the tumour and in February 1988, I had trans-sphenoidal surgery to remove the tumour and part of my pituitary gland. It took until September before I felt completely over the operation and able to return to work. In 1992, my growth hormone level started to rise and an MRI scan revealed that the tumour might be returning. I underwent six weeks of daily radiotherapy which left me feeling tired and lethargic.

Overall, I have improved greatly since the operation. My facial features have softened, my lips are normal, my nose is less fleshy and the ridges over my eyebrows have receded. Some days I feel normal and achieve a lot, but on other days all I want to do is sit around and do nothing in particular. I tire easily and find it difficult to maintain physical activities for very long. My weight has increased considerably, especially the upper body, which I suspect is a combination of the steroids and a less-active lifestyle. Thanks to the radiotherapy, I eventually became growth hormone deficient and started replacement therapy - this has improved my energy level and also reduced my weight a little.

Although my acromegaly is "cured" because I no longer produce excess growth hormone, the removal of my tumour has left me with medical problems, which I did not have before. The weight gain and increase in fatty tissue is one aspect, the chronic fatigue and exhaustion is another.

Steve (from the UK)

*We would like to say a special thank you to The Pituitary Foundation UK, for allowing us to reproduce their Information Booklet. The New Zealand Acromegaly Society takes sole responsibility for producing this publication in New Zealand.*

**Disclaimer:** *All information is general. If you or your carer have any concerns about your treatment or any side effects please consult your GP, endocrinologist or neurosurgeon*

# THE NEW ZEALAND ACROMEGALY SOCIETY

The Information booklet was provided as part of our support services. We hope the information helped you. If you would like to help us, your donation will assist us in continuing this service.

If you are an acromegaly patient or a family member, or a health professional involved in the treatment of acromegaly, we welcome you to join us as a subscribed member of The New Zealand Acromegaly Society. This will greatly help our awareness efforts, and assist us to provide further support services.

Please complete the form below and send to us at:

**The New Zealand Acromegaly Society, PO Box 302, Morrinsville 3340**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Contact Details: Home Phone \_\_\_\_\_

Mobile \_\_\_\_\_

Email \_\_\_\_\_

Do you have Acromegaly?

Are you a family member of someone with Acromegaly?

Medical professional involved in the treatment of Acromegaly?

Other  (Please specify) \_\_\_\_\_

Comments \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Subscription (\$20 per person annually) \$ \_\_\_\_\_

Donation \$ \_\_\_\_\_

**Total** \$ \_\_\_\_\_

Receipt required: Yes

No

*Please make cheques payable to "The New Zealand Acromegaly Society"*