

Acromegaly – Kel



In January, 1996, I went to a new GP complaining of tightness in my hands, similar to a glove full of water. I had been a number of times to my long term family GP but I was concerned with the lack of success in getting a clear outcome as to what was causing the symptom of my hands. Up until this time the symptom had been intermittent but now it had reached a new level as I was unable to make a clenched fist and I knew something was wrong. I thought it was fluid retention however following some astute recognition of symptoms by this new doctor and a follow-up blood test I was diagnosed with a pituitary macro-adenoma.

The tumour was the size of a golf ball, slightly in excess of 3 centimetres. It had filled the pituitary cavity, crushed my pituitary gland and encased one of my carteroid arteries and some of the nerve endings behind my left eye. When told I had a tumour I sucked in a few deep breaths and asked “is it malignant” but had to await a few days for an informed response from the experienced neurosurgeon I was referred to. My discussion with this specialist provided a factual brief about my condition, recommended treatment and any potential complications. I really appreciated being advised clearly of what I had and how to treat it and this enabled my positive attitude for the proposed surgical treatment.

I entered hospital later that month and had transphenoidal surgery to reduce the tumour size. Whilst a considerable volume of tumour was removed the tumour itself was more firm resulting in the recommendation for a second phase of surgical intervention being carried out. The second round was to further reduce the tumour volume and hopefully improve the effectiveness of the follow-up radiotherapy.

In August 1996 I had a craniotomy and returned to my job three and a half weeks later. I then had six weeks of radiotherapy treatment, with daily dosages reduced in strength to avoid any effects on my eye sight. My left eye movement was temporarily impacted and resulted in me appearing somewhat cross-eyed lacking synchronization with the other eye. I had a new fashion persona wearing a patch over the left eye for a period of some months while it repaired. Whilst the vision has improved it has remained somewhat blurred some 12 year s later.

As of 2009 this tumour has reduced in size however it is still producing growth hormone above the high level for a normal person. I am on a combination of bromocryptine tablets twice weekly and three weekly high dosage injections of LAR Sandostatin seeking to reduce the output of growth hormone. The injections present no obstacle given that I have been an insulin dependent diabetic since the age of nineteen. The issue now is this sustained higher level of growth hormone since the surgery has impacted my diabetic control.

I am experiencing early stages of retinopathy and have had multiple applications of laser treatment to my eyes to restrict the leaking of blood vessels in the eye. The next step is to get my insulin-like growth factor IGF-1 to a lower level to reduce this symptom. I have wonderful support from my treating doctors who are seeking to assist me in gaining access to new and emerging treatments for persons like myself who have not responded to traditional treatments at maximum level of dosage.

At times I do get frustrated that after in excess of twelve years and taking an increasing range of drug treatments for the symptoms of Acromegaly I still have not reached that positive reduction in my growth hormone levels. I still remain positive of an eventual successful outcome.

Whilst this disease, and associated treatments, has made me adapt my lifestyle I will not allow it to dominate every part of what I do. By achieving this measure is *my* measure of success. I remain very active in both my professional and recreational lifestyle. I am adamant that all persons suffering any disease can achieve the best possible outcome through a combination of (1) positive attitude and (2) clear understanding of the facts and accepting responsibility and active participation in their own treatment. In addition I have been fortunate in having the loving support of my immediate family.

I strongly recommend the active participation in the Australian Pituitary Foundation meetings. It provides sufferers and their families with the support and direction to enable them to make their own informed decisions regarding treatment options and optimizing their lifestyle.

Without wishing to sound too philosophical I offer the following sayings that I have found useful in meeting my challenge.

“Life is five percent about what happens and ninety-five percent how you react to it.”

“If you think you’re done you’ve lost.”

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