

Acromegaly – Ron Waters

Inaugural Secretary of the APF



In February 1986 I was diagnosed as having acromegaly - a complaint which I had had, with hindsight, for a number of years - as I learnt at the time of diagnosis. I exhibited most of the usual classical features – large hands and feet, incorrect bite, protruding jaw, high forehead, sleep apnoea, oily thickish skin etc . These symptoms had gradually become evident over the years but I assumed they were just part of my make-up.

For some twenty years I had been attending the same GP practice and so those whom I was seeing would have witnessed only the gradual change that my family and I witnessed. Near the commencement of 1985 my doctor, who had been attempting to treat me for a skin cancer on my lip for some time, finally sent me to an experienced dermatologist. This specialist also had no success with treatment and advised me to visit a surgeon to have the problem surgically removed. That I did that same day.

The surgeon gave me the option of having the procedure carried out then and there in his rooms or I could attend hospital. I chose the former after he explained what would occur and was also asked if a lady who had just finished her final medical exams could observe. Thank goodness I agreed because as soon as she entered the surgery and saw me she raised a few questions with the surgeon. Because of her observations I was referred to an endocrinologist where the final diagnosis was made - a diagnosis that gave some feeling of relief because I was aware that things were not as they should have been. Acromegaly is an insidious complaint which “sneaks up” on the patient and in my case was present from about 1972. (Being a school teacher the annual school photos give proof to this.)

Following diagnosis, treatment was begun with bromocriptine - a drug that I found most difficult to tolerate - even in small doses. However, I must hasten to add that I met others who suffered no side effects at all. Towards the end of 1985, because of my reactions, it was suggested that I enter the clinical trial for Octreotide (Sandostatin) which was being conducted at the Garvan Institute of Medical Research. No words can express my gratitude for this opportunity, for the care received and for the positive outcomes experienced.

Firstly I met others suffering the same complaint. Up until this time I knew of no fellow patient. This meeting brought about a growth in confidence as we swapped stories. Secondly the injections of the drug brought about a dramatic improvement in my sense of well-being and over a period of time many symptoms became less obvious. Eg - hands and feet became somewhat less large.

Another less obvious problem that I had to endure was that I had completely lost the ability to sing – something that I had always enjoyed. This ability would gradually return over a period of time – much to my pleasure.

I only know of three side effects that affected me from Octreotide. The first was a slight pain in the stomach that lasted for about an hour after the first injection only, the second was that I experienced somewhat loose motions for a couple of days and the third was much more serious – the development of gall stones which led to my gall bladder having to be removed some years later.

At the end of 1989 my trial period ended and was followed by surgery and then radiotherapy. Because of radiotherapy as then given, I am on all hormone replacement therapy – excepting for growth hormone which my monthly injection keeps well and truly under control.