



Cushings – My Story – Jack

At the time of writing, (May 2008) I am 57 years of age. I am currently in good health, reasonably fit and fully employed in my own business working about 60 hours a week. This was not always the case.

Approximately 15 years ago about 1992 I needed an operation to remove a benign growth from my pituitary gland. I was 42 at the time.

The events leading up to this:

I have always been fit and active. I enjoyed an active sporting life being a skier. On an average day I would ski for 6-7 hours and not think twice about having a number of late nights. Over the years, between 39 years old to 42, I was slowing down too quickly. Various visits to the GP put this down to “old age”, an identity I refused to accept. I was making mistakes at work. I was falling asleep at the dinner table, a most embarrassing habit during a dinner party. My muscle tone was deteriorating and I found trouble lifting heavy objects.

I could only ski for 2-3 hours and was continually tired. Eventually my GP after about 4 years decided that I should see an endocrinologist. This doctor was a professor and meant to be a top person. He took blood and checked all sorts of chemicals. The most frustrating part was that he sent me for a blood test and they took one sample when they could have tested for over a dozen things at once. This testing took over 18 months.

During that time I also had extreme constipation, and was also seeing a gastro specialist. He had already decided that I needed to be operated on and would probably lose a part of my bowel. My life was falling apart. My business was not producing, my sex life was non-existent and my wife, also a GP, was tearing her hair out with the treatment I was getting.

One day as luck would have it we saw a photo of me in a local newspaper. It showed a round moon faced person with a very pale almost yellow complexion. When my doctor prescribed the next blood test my wife added a test for cortisol. The results were sky high. The specialist was amazed and angry. At this time my skin was also very brittle and I bruised easily. A small knock as I passed through a door frame resulted in a bruise. My wife said I had classical symptoms of Cushing’s disease. The specialist was still not convinced. He ordered me to have another test. This one consisted of passing a catheter through my arteries from my groin to my brain to sample the hormones that my pituitary was producing. Eureka, he was finally convinced that I had a pituitary problem. At the same time I also changed endocrinologists and was booked in to have surgery. The surgeon removed a cyst from the pituitary gland through the nose. I also cancelled all work with the gastro specialist. If he had operated at that time I possibly would have died on the table.

The pituitary operation was a great success. After a week in hospital I was told that my entire pituitary on the left side was removed. I would need to take cortisone for some time as my body was not producing it. My facial symptoms returned to normal fairly quickly. My bowel problems also resolved.

But this was not the end of the ordeal. There was a great deal more to find out.

The almost total removal of my pituitary caused other problems. My body was not producing growth hormone or thyroid hormone. This fact also took a reasonable time to diagnose. There was a great deal of wait and see. The operation was a success and the body should return to normal. I now looked "normal".

It took about another 3-4 years to convince the various doctors to allow me to use growth hormone (GH) to supplement my non-existent production of the hormone. Once this was prescribed, and in conjunction with Thyroid tablets, I started to become my old self. (I must point out however that I pay full price for the G H. Sometimes I think that the hoops I need to jump through to obtain the product are especially designed to deter me from using the product.)

The whole process from the time I started to feel ill, through the diagnosis, and then the recovery phase took about 7 years. It also was partly responsible for my divorce.

Now at 57, I own 2 businesses', go to the gym 3 times a week, I am in a long term committed relationship and ski 6 hours a day. I still see my endocrinologist once a year. We are growing old together.

What does the future hold? Hard to say. The last MRI scan showed a tiny growth in my pituitary area. Will it become large enough to need surgery? Time will tell.

The most important thing that I can do is to stay fit and positive. To enjoy all the things I like to do. To live my life as if each week will be my last.