

Support of Loved Ones

I find it a bit difficult to put in words my story about acromegaly, but I would like to try.

To start out, I had a lot of headaches and my doctor would try to treat them, but nothing worked that well to relieve them. About a year later I had an MRI done. The following week I had to go back for another one. When I got the results, I was told I had a growth on the pituitary gland. From there I had to see an endocrinologist. She is a very lovely lady and I always feel comfortable with each visit to her. She got in touch with doctors in Halifax and one in St. John about my condition. By this time, I was told I had acromegaly.

In June 2004, I had the growth removed from the pituitary gland. As time went on, I had more blood work done and each time it showed that my IGF-1 levels were not coming down very much. In February 2005, I started on sandostatin Lar 10 mg once a month by injection. Later, it was increased to 20 mg and for the past two years I have been getting 30 mg a month. Still my IGF-1 levels were not coming down like the doctors were hoping.

The doctors decided after this they would like me to have radiation treatment. In April 2006, I went to Halifax for 25 treatments. Before I travelled to Halifax, I did a lot of thinking about how will I pass the time, being so far from home and I wondered who might come down each week to keep me company.

I was very fortunate when the time came, as I only had to stay alone for 3 days during the whole 5 weeks. Between my husband, two of my sisters, and a close friend, they worked it out who would come down and when they could come.

During my last week of treatment, I got some very heartbreaking news. One morning after I finished having my treatment a couple of nurses took me to a quiet room at the hospital and there was my husband and our pastor. I wanted to think that this was a normal visit, but I could sense that something was wrong. They gave me the news that our son passed away. He was our only child and gone at age 31.

I was told that I could finish my treatments that week or I could go home and come back the next week to finish. I chose to stay and get them done because I knew if I went home I would not want to come back.

My symptoms of acromegaly included headaches, my fingers got bigger and my footwear changed from a five and a half or six to a seven. Sometimes I have a hard time finding shoes that are comfortable.

I am still taking 30 mg of Sandostatin LAR monthly. My doctor keeps my IGF-1 levels, MRI's, and visual fields monitored.

I am thankful to God for each new day I have. I couldn't make it without strength from God. I appreciate all the great doctors and nurses that I have seen during my check-ups and I am grateful for all the support from my husband, family and friends

Clinical Pearls

- The support group encourages spouses and family members to attend so they will have a better understanding of acromegaly.
- Attendance of patients and families to the support group meetings can lead to better communication and may help families to cope.
- It is an opportunity for family members to ask questions in a non-clinical setting. When able to express feelings in a supportive environment, you gain energy, humour and a sense of peace.