



Hello everybody,

My name is Barry Varga and I have been diagnosed with a form of ALS called Progressive Muscular Atrophy (PMA). PMA affects only the lower motor neurons so the upper motor neurons (located in my head) are still functioning. The lower motor neurons that go from my spine to my muscles are not functioning.

I am a native born Calgarian and have lived here most of my life. I have been married for 21 years to my best friend Judy who is now my primary caregiver. We have two beautiful daughters aged 16 and 10. We live very close to Fish Creek Park which has provided us a great setting for lots of outings over the years.

I spent my early youth working in the oil patch. With the end of the oil boom in the early eighties, I was quickly without work. That's when I decided to go back to school and graduated with a degree in Computer Science in 1986. Since then, I have worked in the computer software industry for some of the finest software shops in Calgary. A partner and I even did a stint running our own software shop for six years. I was last employed by TransCanada when I started experiencing chronic back pain. Then I started to lose strength in my leg muscles. I was diagnosed with PMA in April 2008 and went on disability in June 2008.

I have been slowly but steadily losing the use of all my muscles. Currently, the lack of leg muscles has resulted in my using a wheelchair. I can still use my arms a little bit and I can still talk (to the annoyance of my family sometimes ☺). Like many of those who have gone before me with ALS, I've gone through the range of emotions. At first, I was shocked. Then I went through a denial stage. I have gone back and forth through various stages of anger and depression. I still struggle with the emotional aspect of ALS but have learned that I have a whole lot of help from family and friends that I never expected. My extended family and my friends have just been tremendous helping me through the progression of this disease.

I feel very honored to have been asked by Jane Rivest to be this year's Ambassador for Betty's Run. I have been a recipient of the most incredible care from the ALS Society. The local ALS Society is a fantastic organization. Living with ALS seems to require an ever increasing number of resources from equipment to people. The ALS Society has been such a tremendous help for me and my family. They have provided much of the equipment for my situation (stair climbers, lift chair, walker, and

wheelchair to name a few). Just INCREDIBLE! I can't say enough about the help I have received from the ALS Society and all the wonderful people who work there.

The ALS Society also hosts monthly ALS support group meetings. These meetings are a great setting for those struggling with ALS, their caregivers, family and friends to meet and have discussions about what has become important to us. It's a place to share information and learn what others are doing to cope. Many of us with ALS have a tough time getting out but I find these meetings are a great help to me.

What I have noticed most since contracting this disease is that ALS is really a hidden disease. ALS is not really noticed by most of society. It affects such a small population that many people know very little or nothing about ALS. Many of us that get ALS spend most of our time at home because it is so much effort to go anywhere. And the disease continues to progress.

Betty's Run is the most important fundraising event for the ALS Society. To continue to provide help for those unfortunate enough to be inflicted with this terrible disease, they need all of our support. I never met Betty but I am sure she smiles knowing that her run is still helping those with ALS.

I hope to see you at Betty's Run in 2009!