

MY HUSBAND HAD CADASIL

July 2006

As some of you may know, I recently lost my beloved husband to CADASIL. It was the most exasperating, confusing, frightening 3 years of my life. Phil apparently had this disease for about twenty years, but we were totally unaware that the strokes he was having, balance problems and the mood swings were all symptoms of this strange illness that we had never heard of. In 1986, Phil had his first stroke he was of fifty one. At that time, no one could tell us why he had a stroke; he had none of the usual problems that lead to a stroke. However, we accepted this and were determined he would not have another stroke. For the next fifteen years, we walked, exercised, watched his cholesterol and did everything we could to keep the wolf from the door. During this time, he had several MRI's and each time we were told that he had brain damage, but no one seemed to know what had caused it. At first we were told it was MS, but the Neurologist ruled it out because he had no other symptoms.

When Phil turned 66 years old, things started to happen that no one could explain. He started limping and dragging one leg. He also became very moody and was making a lot of mistakes driving. The children became very concerned and we started making the rounds of neurologists. The answers were always the same. "There appears to be damage to the brain, which is causing some of his problems, but we don't know what is causing the damage." After about 18 months of this, I decided to be an advocate and made an appointment with Mayo Clinic in Jacksonville, Florida. On the day of his appointment, he had another stroke and was in the hospital. When he came out of the hospital we did go to the Clinic where he was finally diagnosed with CADASIL. Since that day, our lives have been turned upside down. Trying to find information, trying to find out what to expect, and finally trying to cope with the changes in our lives became our main focus.

Each time Phil would go downhill was very traumatic for me. I would have to learn how to cope with another problem and figure out a new routine to cover the new problem. My biggest fear was that he would be a vegetable and suffer a great deal when the end was near. I guess in some ways we were fortunate that we never had to cope with that. He was only unable to eat for one day when he developed pneumonia and ended up in the hospital. He passed away four days later without ever recovering at the age of 71 years old. A part of me is grateful that he didn't suffer, but I am still very bitter that there is still nothing that can be done for people like Phil diagnosed with CADASIL.

My thoughts and prayers are always with our CADASIL family. I feel as though we are a very special group of people who only gain strength from each other. God Bless You All Jo.