

November 2009

We have now over 950 documented cases all over the world. The foundation has worked with New York University on a survey and started a new forum and much more.

It has been two years since I have logged anything down. I work full time and a full time care giver for my husband and run the foundation.

I live in fear each day something is going to happen with my husband and panic daily. It is sometime hard to live each day like this. I have to take my time and try my best to sometimes put on a brave face and go on with life. I never thought I would see my husband alive at 53 years old. We have been fighting CADASIL over 10 years now.

Anytime anyone ask me what I wish for: A cure or treatment for CADASIL.

Steve brother, Victor was diagnosed in 2007 and his sister also was diagnosed the same year. Steve has 3 brothers and 1 sister. 3 out of 5 siblings have CADASIL.

We still see the same doctors and Steve's medicines has not changed much.

May 2008 -

Steve's gait was off and not sure if he had a small TIA. We know he has had several but not to the point of rushing to the hospital. He also has upper respiratory infections. It seemed so hard for him to get over them as his immune system is down.

December 2008 -

Steve has been having night terrors for the passed 4 months. He has fallen out of bed at least 3 times and last time he separated his shoulder. He is very weak and it's hard to get him up form the floor. He went to Physical Therapy and finally healed without surgery.

In February and March of 2009 = Steve started to have small blister on his calf's. They started getting worst and run and looked liked ulcers. They would come and go. The doctors gave us creams, etc. but nothing seemed to work. August he started to go to wound care, 3 times a week for bandages, etc. I was taking him 3 times a week and for over 9 weeks. The wounds are healed but now he has to wear medical hose up to his knees. The problem is he cannot put them on himself. I have to wake him up in the morning before going to work and struggle to put them on. It is getting easier now. We had to go up a size and less compression. Steve has to wear them every day or his blister will come back.

In June 2009, Steve fell and trip over the paper shredder. He called me at work as the Blood was spouting out as he hit an artery in his foot. He is on blood thinners which made it pour out. He had one stitch and then came home. (Thank goodness it was nothing worst.

I do see memory loss is getting worst. He is short tempered and has to have things done a certain way.

July 2009

Steve has lots of joint pain now and he has problems getting up from his chair. It is hard for him to sit low and cannot sleep in bed as he has to sit up.

August 2009 I came from work and Steve was talking about a car accident which happened over 4 years ago. He thought it was just last week. He could not remember one of our daughters name and our grandchildren. I was scared as I thought he had a stroke. I called EMS and found out his blood sugar was below 40 and was going into a diabetic shock. I took him to the E.R. and make sure it was not a stroke as I had taken all the papers about CADASIL with me. Now I have an emergency kit, just in case this happens again.

October 2009

Steve has had problems lying down in bed for this pass 5 months. He was sitting up on the couch at night and slept there. When our doctor prescribed a hospital bed for him and Medicare paired 80% and we have to pay 20% for 11 months and it will be ours. It hurt so much to see him in a hospital bed. Our room looks like I Love Lucy show. I am in a twin bed and Steve is in a hospital bed which is wide, due to his weight. I made sure our room looks very nice. I bought matching bed spreads with tons of pillows so it looks good. We have a small night stand between us, so Steve can get out of bed.

November 2009

we had Thanksgiving and Christmas I am wondering if this would be the last thanksgiving together as I always live in fear of this disease and what it can do.

January 2010

a new year and Steve's legs are blistering again and went back three times a week to the wound care.

February, March

Good news as finally after fighting 13 years there will be a CADASIL conference. Steve is getting worse, his memory is so short. We can watch a movie then he falls asleep and cannot remember that he had watched some of it. He is getting weaker and having problems getting up from the couch. We went to DARS and they will help us with making my life easier in about 9 months as they having a waiting list for terminal ill people.

I mourn each day on what I am loosing. I love my husband!

This is my feeling and I have not edited this at all form the first day I started it, this is how I help others cope and my own family.

March 31, 2010

Billie