

Part 3 of my experience

Let me first apologize in advance: please forgive for any spelling or grammar errors as this come from my heart.

I guess I could say a lot has happened since the last time wrote.

In March 2010, Steve had heart failure. We were in three different hospitals in six weeks. I say WE, as I never left his side, since Steve has short-term memory problems... I was off work for around two months. Even when Steve was in the ICU, I could stay him, as I am his nurse, would measure his intake and outtake, and bathed him, etc. The nurses were thankful for me to do this as it helps them.

Steve has AF (Atrial Fibrillation) and congestive heart failure. It is always something else. The congestive heart failure and heart problems are not in a related to CADASIL. I was so upset emotional here he was fighting CADASIL for over 14 years and now his heart. WHY! WHY! WHY! You see when Steve was tired or was not feeling well or could not walk far, we put it down to CADASIL, yes CADASIL. We had no idea it was anything else. We did find out later that Steve did have a heart attack in the past and did not know it. So if you read this please make sure you get your loved one checked out and do not assume it is always CADASIL. (A hard lesson to learn).

July 2010 was a dream come true, a family conference and scientific symposium was being co-host between us (CTWHH) and ULF). I presented at both the symposium and the family conference. I never have presented before in my life, yes I was nervous. At the scientific advisory symposium, the data from the CTWHH registry matched the data of the scientist; the age diagnosed the symptoms, etc. Wow! I felt like I was in a dream and someone would say cut it will be over. It was wonderful to meet people and doctors all over the world. For more information on the conferences go to the website and see the reviews.

I was asked to be on the ULF Board of Directors in the summer of 2010, which was quite an honor. I accepted the position, as I wanted to represent CADASIL as well as the fact that the ULF receives donations earmarked specifically for CADASIL research. The ULF accepts international grant proposals for CADASIL research. The ULF's prestigious scientific board periodically reviews the proposals and awards CADASIL research grants. Unfortunately, in the summer of 2012, I had to make a tough decision to resign from the ULF Board of Directors due to family obligations as well as to focus all my efforts towards CTWHH.

When CTWHH was originally organized, due to limited manpower with an all-volunteer staff the nonprofit could not take large donation. The Board of Directors still believes that there should be no paid staff so that 100% of all donations are for CADASIL...not to pay a salaries, etc.

A new web page was designed that shows individuals where funds can be donated directly towards CADASIL research to a variety of scientists, doctors, organizations, etc. around the world.

Life goes on no matter what. Steve seems to be stable finally with CADASIL, heart problems, diabetics, etc. Considering everything that has happened, Steve takes his medicines and is always in a happy mood, jokes, and laughs all the time. He says he could be hit by bus tomorrow. The saying is true – Laughter is the best medicines.

Finally, I am learning to go with the flow of life and try to not worry. It is hard not to worry; it's hard not to worry when I come home from working all day if Steve has had a stroke or not. It's hard not to worry if Steve does not answer the phone during day, is there something wrong? It's hard not to worry to know what is going to happen in the future. However, I try not to... We have our up and downs. Over the last 14 years my coping

skills have been spending as much time with Steve, my family and volunteering with the nonprofit I keep myself busy..

In 2011, we went on vacation to England. When we were in England, I seemed to try not to worry because of what could happen if Steve gets sick. No one's know about CADASIL, the medical care is not advanced as the U.S.A.

While in England we had the opportunity to visit Paris, France as the French team gave me an open invitation. Little old me had started a website in 1997 to help my family and others and now we had the chance to meet the top-notch specialist of CADASIL who had assisted in my husband getting diagnosed meeting them was a dream. The French Group (foundation) wants to work with CTWHH towards an r treatment or cure for everyone involved as we are all in this together. It was like meeting a movie star when Professor Bousser walked in, as she was the one who had called me in 1996 and helped Steve be diagnosed (see part 1 of my story). Please go to the newsletters for more information.

We all have our up and downs even running a nonprofit. This has been a rough year for CTWHH. I keep thinking all we want to do is to assist with CADASIL. No matter what others say, we all are in this together and we are all reaching for the same goal for a cure or treatment for CADASIL.

September 2011, Steve celebrated his birthday. We are blessed to celebrate his 55 years of life. Since his dad died at 52 years old of CADASIL, each year it's a celebration. We try to go away, which I call our escape just for different scenery, and this time we went to a pine forest for two days. I know Steve must get tired of being in the house all day.

October 2011, my oldest daughter, Natalie, 26 years old has started sigs of CADASIL. Oh! A mother I hope not but as a person who deals with a nonprofit she probably does. To cope I file it in the back of my mind and try to carry on especially since she has two children.

End of the year 2011 Steve seemed to be getting very frustrated and very upset at things when he could not remember. He could think of the word but it would not come to his lips. I would not give him the answer as he had to think of the word and I would give him clues.

Aleaha our granddaughter, 8 years old asked if she could type on the computer. It read, "Cadasil very important I hope to help sum day because it would help people." She even spelt CADASIL correct.

New Years we went away to the Texas coast just to relax and a different environment. We walked on the beach and just talked about everything and collected shells.

I guess it was around January my seven year old granddaughter had call me on my cell phone and she said her mommy 26 years old, had pulled over in a parking lot and she would not wake up and was behind the wheel of the car. I put the flashes on my car and sped across town to that parking lot. My daughter, Natalie was so groggy and might have passed out while driving and was smart to pull over, as she was not feeling well. Aleaha, our granddaughter was also watching her young brother, Darrius in the car.

We took her straight to the E.R. She had a CT scan and yes, it showed white matter on the brain. Oh, my WORD she is a single mother and has two children. She was referred to a neurologist. My daughter also was having headaches for the past 6 months prior to passing out.

The neurologist ordered a MRI. When my daughter went to see the neurologist, he suggested giving me a copy of the MRI CD for me to review. I'm no doctor I thought doctors were supposed to do this.

The next time my daughter visited her neurologist, I went with her. The doctor suggested for Natalie to be tested for CADASIL, I felt the ground would open up and swallow me up. I did mention to put her on migraine prevention medicines which the same her dad was on. He took my suggestion. You see you have to be an advocate for your family, which I have always said.

In March 2012, Natalie was rushed to the E.R. for a migraine about a month after the episode. I took the emergency card and mention to them what not to treat her just in case she has CADASIL. After two hours in the emergency room, she was sent home and the migraine lasted for three days in a dark room. Natalie wanted to be tested. Oh my word, hell on. I do not want to know now if my daughter has CADASIL as she has two beautiful children.

Natalie followed through, saw a genetic counselor, and was given the choice to be tested. She wanted to know. The day the blood was drawn Natalie had to give a copy of her dad's blood test results showing Steve's mutation to be sent to Athena Labs with her blood test?

Yes, Natalie test came back. I cried, yes I thought about my grandchildren what about Steve how is he going to cope with this. I was at work when I found out and thought history was repeating itself over again. WHY! When I got home, I looked at Natalie's result. I hugged her and wish this was not happening. Natalie was very positive and said what the difference; already I knew I had CADASIL. I am very proud of my daughter.

In the results packet there was something that caught my eye and it read, *"It is important for you to know that there is nothing that you or your family did that caused you to inherit the CADASIL gene. We have no control over the genes we inherit, just as we have no control over the genes we pass on to our own children."*

This paragraph sums it all up for me and it helped me tremendously to know about my feeling of guilt should not happen. I kept rereading this and repeating this paragraph for about a month.

I really thought the depression would hit Natalie but it changed her life for the better. She started college, and started to plan her future with her two children. I know when my grandchildren are older and if they do have CADASIL then hopefully there will be a cure or treatment and maybe even for my daughter.

Steve gets very tired so easily. He has to take a nap during the day

In May, Steve's mother broke her leg who lives in England. Steve flew out a week before I did. How I tried not to worry for that week. I was apprehensive he would have a stroke or attack.

Steve's younger brother, Victor has CADASIL. He is disabled due to a major stroke. He is very unsteady on his feet for a 54-year-old man. He did have a TIA when we were there and keeps having them. Steve sister, Lorraine the baby of the family also has CADASIL. She gets very tired but has to work to survive, as the cost of living is so high. It is so unfair to see his family suffer.

I did notice the last week in England Steve started to slobber on one side and I just thought he was tired I had no idea what was happening.

You have to be at your own advocate, you have to take control of the situation.