

October 8, 2006

I will try to tell as much of the journey my brother, **Daniel and I have been on since being diagnosed with CADASIL**. Daniel was the first one in the family officially diagnosed with the disease. I believe it was in approximately December 2004 from what he has related to me, that he believes he had his first major stroke. It affected his left side leaving him with complete numbness on that side and made him slur his speech. This was especially hard on him as he is left handed and it made it especially hard for him to try to write. He had to start printing everything and even then it was very laborious for him. He recovered enough to continue to work (he worked at a hospital and has been a male nurse for years) since he had the stroke.

In June of 2005 he had been having trouble with his memory some and the hospital used that as an excuse to fire him after about 23-24 years on the job with no performance issues. This totally destroyed his faith in himself and sent him into a deep depression. He then suffered several more smaller strokes and continued to have trouble remembering things and he was even hospitalized because of the depression. No one could find a reason for his problems. In the meantime he became totally disabled and could not return to any job. Sometime around December 2005 after numerous tests, Daniel was finally diagnosed with CADASIL. At last he had an answer to why he was having so many problems. At the current time he is on (by his count) approximately eighteen different medications, several to help control the Alzheimer symptoms he has. He is trying to fight this disease with everything he has and hopes every day for a cure. He calls me quite often and we talk and he rarely ever worries about himself, but always tells me he is so sorry I have tested positive for it and he doesn't want to see me go through what he has. It takes so much from a person.

He has taken to putting his thoughts down on paper into musings or poems about how the CADASIL has affected him and what it has taken from him. I am going to attach several of them to this email for your use. Sometimes when he calls me with a new one he has written, I just fall to pieces and cry. I know how hard it was for him to even attempt to write it down. He goes to a special place several times a week for support and help called Soft Voices and one of the ladies there has started to write them down for him while he dictates them to her. The Library in the town has now put one of his poems on display. I am very proud of my brother and love him very much! He is my younger brother and it kills me to see him having to go through this. No one deserves to suffer so much. He is only 51 years of age.

After Daniel was diagnosed he was very insistent that maybe I should get tested because I have had a lifetime (as he has) of migraine headaches and other illnesses that no doctors could find a cause of. In 1995 I had a spell (for lack of any other thing to call it) where I awoke from a sound sleep very dizzy, nauseous, throwing up and with the worst migraine I had ever had. The symptoms continued for a week. My wife, Debbie, took me to the doctors and he sent me to an Ear Specialist. He ran a battery of tests on me and had an MRI done of my head because he suspected a benign tumor on my auditory nerve of my ear. When I went for the result, he looked at me and asked me "how long have you had MS?" I said "excuse me?" He said "haven't you ever been told you have MS before. I told him no and he told me that the back of my brain had numerous 'plaque' spots on it and that was indicative of MS. Then he referred me to an MS specialist who ran a battery of test on me and finally decided that I did have "some of the symptoms, but not all of them" to make a positive diagnosis. I was then referred to a neurologist who put me through more tests and decided I had a combination of Fibromyalgia and migraines. I have been being treated for that ever since. No one had ever tried to find out why I only had these 'attacks' in my sleep and then they were always followed by a bad migraine and they were/are always proceeded by auras. I finally went to my doctor and told him of Daniels diagnosis and told him I wanted a referral to another Neurologist and wanted to get to the bottom of this. He agreed. When I told Dr McNutt of Daniels diagnosis of CADASIL ,he was very familiar with it because he had been studying it at the University Hospital here in Colorado for the last year. He had tests run on me and found I have irregular brain activity during sleep and that causes my dizziness, nausea and migraines. They are kind of like a seizure. I am on medication for it and it helps, but I still have them from time to time. I also had the blood test run and was found to be positive for CADASIL. My MRI showed that the 'plaque spots' I have are from having had numerous TIA's. I have some word memory recall problems because of them. I am 56 years old.

Daniels wife, Cornelia, is a special person. She has to hold down a full time job, take care of Daniel and is at the current time taking care of her adopted brother who is in stage four Cancer and has only a short time to live. I know that it is hard on her when she sees the two of us together. How could she not wonder why Daniel has the CADASIL so bad and I don't and I am older. I have questioned that myself. I guess that only God knows why. I've seen him suffer so much and have told him that if I could take some of it from him I would. No one should have to suffer that much.

Currently our sister, Karen, is going to be tested I believe this month. She has a history of migraines too. She is 54 years old. Our two other brother (one is 49 and the other one will be 60 in November) don't seem to be interested in finding out. Our mother, we believe, passed it on to us from her mother. They both suffered migraines and they have run in that side of the family way back. My mother died in her sleep of a massive stroke (she had had some TIA's and small strokes too) at the age of 67 and with complications of Diabetes. So the only generation alive now is ours so we can only speculate.

I hope this letter isn't too long and you can use it in your newsletter and on your website. If anyone wants to contact me for any reason, I would be more than happy to correspond with them and share information on this disease. Daniel has given you permission to publish or use any of his poems I send to you.

Thanks for your time, Jim Spickard, Highlands Ranch, CO, red62tbird@qwest.net

FEAR

It's very scary!
As big as the Empire State building.
Black.
Smells like a skunk.
Sounds like a screech
Tastes like okra.
Feels like a lion trying to eat me,
and I'm all alone.

When I'm with Lincoln, my beagle-pit bull friend,
I cry.
He comes and nuzzles me.
Only problem, he's scared of the stairs
so I can't be comforted up there.

I wish I wouldn't have gotten it (Cadasil),
but my grandmother had it too.
It's taken so much away.
So many meds!
Lost my ability to drive,
to ride my motorcycle,
to make love.

We want to retire to Westcliff.
It's pretty mellow there in the mountains,
South Park area.

And my brother, he's got it too.