

## A CADASIL Family's Story

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This is my story about our family and CADASIL. When I think about telling you this, I do not know where to start.

CADASIL (Cerebral autosomal dominant arteriopathy with subcortical infarctions and leukoencephalopathy), a just recently identified leukodystrophy, is a diffuse disease of small arteries predominating in the brain. It starts during mid-adulthood and is characterized by recurrent ischemic events (transient or permanent), attacks of migraine with aura, severe mood disorders, subcortical dementia and, at MRI, a white spread leukoencephalopathy.

I met my husband, Steve, in England, we were married and celebrated our first anniversary in Texas. Steve is a British citizen and left his family to move to Texas. Our marriage is wonderful, and we have been blessed with two daughters, one in 1983 and one in 1987. We lost our son as a preemie in 1985, the same week Steve's father had a stroke and died.

They told Steve his father died of a stroke. He had had headaches and seizures from a car accident when he was in the British police force. They also told Steve's family he had pre-dementia. We knew he was very sick and each year his mental condition got worst.

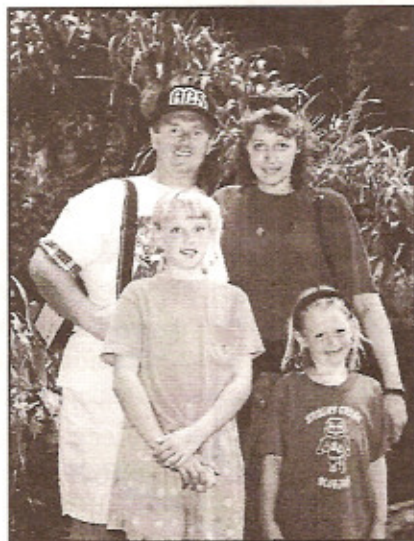
My husband has always been in great health. He even had perfect attendance at work until 1994. In the fall around the holidays, he had a headache attack that put him in

the hospital for nearly a week. They could not find the cause. All tests were negative. I do remember his words to me, "Just let me die," as the pain was so bad.

In 1995, the same time of year, the headaches recurred. This time he was referred to a pain clinic and CT scans were taken, which came back abnormally. Then an MRI came back abnormally with white matter lesions. He was immediately referred to a neurologist, whose words were very supportive but not promising. We went through tests, but nothing came up.

I contacted the United Leukodystrophy Foundation and was networked with other families with undiagnosed adults. I wrote to eleven people. Out of the eleven, I heard back from eight people. This is the way I coped.

My husband continued functioning the best he could after finding no answers through migraine shots, jabs and tests. I am no computer whiz, but I got on the Internet with no training and looked up excessive white matter, anything from the results of MRI and CT scans. I sent more than 200 e-mails out with my husband's medical history and asked for help. I had very good response from doctors and as well as people like me. A mother whose son was sick and had undiagnosed leukodystrophy



recommended a doctor she knew. She was an angel, because that doctor was willing to read all my information and even called me at work. He said he thought my

husband had CADASIL but did not know too much about it.

A doctor at the Kennedy Institute helped continue Steve's testing. Records were sent to Paris France to a professor doing research there. The professor requested a copy of the MRI and to have an unusual skin biopsy done. We looked for two months before finding a place who could do it. My father-in-law's medical records were also sent to her. She and her staff were so wonderful helping me cope and learn about CADASIL. In the end, both my husband and his father were diagnosed as having CADASIL. The test which finally diagnosed my husband was an electron microscopy skin biopsy.

There are no known medicines for CADASIL as of yet, but my husband is on daily medication to prevent migraines, help circulation, and prevent strokes. I would be happy to communicate with others wishing to learn more about or cope with CADASIL. Please contact me at 3605 Monument Dr., Round Rock, TX 78681; phone 512-255-0209; e-mail <CADASIL101@hotmail.com>