

Susan Troutman... Nurse, Student & Mom

Susan Troutman answered our call for Good News Stories and was kind enough to tell us her story via email. Susan wants people to know that while Chiari is serious, it does not have to rule your life:

Let's start with your life today. You sound like a busy woman, what all do you have going on?

S: I'm currently a full time student pursuing a master's degree in nursing at the University of North Carolina Chapel Hill. I hope to graduate in May of 2005 as a Family Nurse Practitioner. I live 2.5 hours from campus and commute early Tuesday mornings to attend class from 9 a.m. until 4 p.m. I stay over night and go to class all day on Wednesday and then return home late Wednesday nights. I see patients in my community 1-2 days a week. I have 4 children, Elizabeth, 19, a sophomore in college at UNC-CH; Jonathan, 17, a junior in High School; Erika, 10, in third grade; and Ian, 8, in second grade. (Ian and Erika were adopted after my surgery) During this time of my schooling Rick, my husband, is shouldering the bulk of responsibility of extra curricular activities of the three youngest children. During the school year, I eat out with Elizabeth on Tuesday nights and touch base with her.

When and how did you come to find out you had Chiari? What type of symptoms did you have?

S: I had quick, stabbing headaches at the base of my skull traveling up to the top of my head. I knew they were not the typical headaches so I went to my family practitioner. After a referral to a neurologist, I was surprised with my neuro exam. I hadn't noticed I would lose my balance when I closed my eyes or that I couldn't touch my nose accurately. By the time I had surgery, I had lots of balance problems. My proprioception was off so I was a messy cook! I had double vision and would turn a book at an angle so that the second image was between the lines. Every cranial nerve except 1 and 2 were involved. The headaches were more like pains, they only lasted seconds. Some days I wouldn't have any and then other days I could have 20 in an hour. When I stopped breathing briefly, I knew it was time for surgery.

Were you a nurse at the time?

S: I was a registered nurse working in the neonatal intensive care with two young children. I knew they were not the typical garden variety headaches. But because I was working with young infants I was not up to speed with adult problems. I didn't know what was wrong but knew I needed to see someone about them.

What did you think when you were first diagnosed?

S: I had my first MRI in 1986 or 1987 when there were only 3 machines in my state. The Docs at work had heard about it but that was all. That was my first hint that this might be serious. I was surprised and not really scared. I didn't know a whole lot, the Dr. said it would progress but he didn't know how fast. He said that if and when the symptoms were severe enough, I would need surgery to fix it. I didn't ask a whole lot of questions I guess I was so surprised that there was something really wrong. I went straight to my nursing and neonatal text books but they didn't have much except a definition. The internet was not available. If it had been, I probably would have been more concerned.

How did you pick a doctor?

S: My family practitioner sent me to a neurologist in private practice in Durham North Carolina. When I moved 1.5 years later, I asked physicians in the area who they would recommend if their patient had a weird neurological condition and the same person was mentioned several times so I went to him. Later he referred me to a regional medical center when I had post op problems. One of the doctors there was not a good match for me. I am now seen occasionally by one of his partners and we have a good working relationship. I feel that it is very important to have a good open relationship and sometimes you have to hunt to find that provider.

Was the decision to have surgery an easy one?

S: I didn't have a lot of pain, mostly balance, coordination, swallowing and numbness problems. But when I stopped breathing unexpectedly I knew it was time. Breathing is something you don't play around with. I had surgery within 3 weeks.

Was your recovery quick?

S: I was home in 5 days and up to the full activities of a mom and mom's taxi within 14. I did my chores slower and it was awhile before I could actually see what was on my dinner plate because my neck was so stiff!

Do you have any symptoms or limitations today?

S: I have to get my rest or I get phantom pains in my arm or leg. A Valsava maneuver, when you strain like when blowing a balloon or on the toilet, is an absolute no-no for me. Just a few seconds of increased pressure in my head will cause several days of a flare up. If I sleep on my back, portions of my legs are numb for a while in the morning, no one is sure why this is, but the MRI is OK with no syrinx as of 2000. Jogging or racquet sports cause flare-ups as well as any impact to my spine/skull. I currently am having problems with headaches 18+ hours a day, not like my pre-op ones. I have been told they are a variant of cluster headaches. I haven't seen my neurologist in 4 years and I have an appointment to see him in about 6 weeks for the headaches.

Do you consider yourself lucky?

S: Yes. I feel like although I have residual problems, they are manageable if I don't step out of my bounds. I can do everything thing I need to, and much of what I want to. In 1996 a wonderful thing happened, we got the internet and I learned about what aggravated other people's symptoms and the coping strategies others were using. But the internet can scare a person. I think the people who have lots of problems

are more active on the net than those who have good results. It was good to have contact with others with the same diagnosis. My husband and I went to Kazakhstan for 6 weeks to adopt our 2 youngest children. I never thought I would be stable enough to leave the country or go back to school. Now I'm back to school 20 years after graduating with my bachelor's degree and 16 years after surgery! I think I'm a better person and my core values are better reflected in my life than they were before I began walking this path.

As a medical professional, has your experience changed how you interact with patients?

S: I am more sensitive of how chronic pain or illness affects all aspects of a person's life. I learned that weird symptoms that come and go should not be dismissed quickly. I try to listen carefully and understand what my patient is saying instead of jumping and filling in the blanks myself.

What would you say to someone who has just been diagnosed?

S: There is a big support family out there on the net. Take this one step at a time, one day at a time. Don't overlook the daily blessings God gives. Everyone is different and you know your body better than anyone else. You may never need surgery but if you do, there are good resources to find surgeons familiar with the procedure. Take the time to find a neurologist and surgeon you are comfortable with. Arnold Chiari can be scary but you are you, the disease does not have to own you. That is hard at times when things aren't going well, but take control of what you can. Accepting what I could and couldn't change has been the biggest challenge. After I accepted my limitations and didn't fight them, I rebuilt my life

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