

Christine Marchesano

Christine's Makeover

*My brain surgery testimonial at
The Chiari Institute-May 2, 2007*

1/13/2008



Fall 2007



Christine and Vince Gill



Taken in March 2007 at the Vince Gill Meet and Greet before the Concert.



*God Grant Me the Serenity to Accept the Things I Cannot
Change,
The Serenity to Accept the Things I Can,
And
The Wisdom To Know The Difference!*

Major events in our lives, no matter how traumatic, often turn out to being a blessing in the end. The outcome also alters the quality of life, our perspective of us and our attitude concerning the situation. Such was true, when I was diagnosed with Ehler's Danlos syndrome, cranial settling and associated Chiari 1 malformation, in March of 2007.

Facing brain and spinal surgery, in May of 2007, although was very scary and frightening, both for me and my family, it was something I knew I had to go through with an optimistic attitude. I also knew I had to face this ordeal head on and go through surgery, if I was going to get physically healthier and stop the progression of the cranial settling.

However, my journey with dealing with a physical alignment, did not start when I was diagnosed with EDS/Cranial settling at TCI, it began at birth, when I was born with Cerebral Palsy and scoliosis 36 years ago.

In answer to Dr. Bolognese's question at my sixth month appointment "How has this experience improved the quality of your life?" I firmly believe that because of the Dr's intervention, the support system I have and my determining will and faith, this surgery has allowed me to look in the mirror and be confident with the person I am and break free from the emotional and physical scars of my condition I was born with.

This is my story and it is my hope that by sharing my experience, with Chiari and having surgery this will help support those who are at the beginning of the road facing similar situations. Fear of the unknown is frightening ,and not knowing what came next in the middle of everything, was nerve wracking. Thus, I am now eight months past my surgery, feeling great and enjoying life again. Here is my story.

Medical History

I was born 3 weeks early on July 17, 1971 with a condition known as Cerebral Palsy which was caused by the rubella rash my mom had acquired during the pregnancy. Also, the pediatrician advised her at some point not to undergo another pregnancy, after mine, because the birth of that child would be traumatic. The baby would need to be completely transfused at birth. During the delivery, the umbilical cord became wrapped

around my head, cutting off oxygen to the brain.

As an infant, there were also early signs that my parents noticed, which pointed out that there was something wrong with me. The red flags included: I would not respond to sound only to the light, excessive drooling, my fingers and toes were contracted and curled up, I was unable to sit up and support myself, excessive sleep, I had long hands and feet and had trouble crawling and moving on my own.

At the advice of the pediatrician, around nine months, a complete physical and neurological work-up was done at Albert Einstein Medical hospital, Bronx New York. It was here that they diagnosed me with Cerebral Palsy and found that many of my symptoms were caused by fluid buildup at the back of the eardrum. To help drain the fluid, Dr's placed myringotomy tubes in both ears. Once these were placed and I was sent home, we were then referred to the Burke Rehabilitation center in White Plains, New York for a further extensive evaluation to find out the extent of my disability. It was founded that I had significant speech deficit and a minimal hearing loss. and the motor deficit impairment caused by Cerebral Palsy was only 20%. Given the fact that I was diagnosed in the 1970's, when little was known about birth defects, specialists were uncertain about what the patient's prognosis would be and how successful the life a handicapped baby would turn out. However, at the advice of Burke Rehabilitation from 2-5 years old, I went to the St. Agnes Children's Unit, in White Plains NY, were I received extensive speech, occupational and physical therapy throughout the day at the hospitals all day nursery school program. It was an early childhood two year, nursery school rehabilitation program, on an out- patient basis for children who had neurological and physical handicaps like; cerebral palsy and spine bifida.

What symptoms were you having that lead you to your diagnosis?

My symptoms with chiari 1 malformation associated with EDS, and cranial instability began abruptly two years ago in 2006 with episodes of un-explained vertigo, dizziness, severe pressure type headaches, chronic fatigue and walking difficulty. These symptoms, slowly and progressively became more and more present, to the point where walking and doing everyday tasks became extremely difficult. At the onset I went to an ENT specialist, to have my ears examined and to find out why I was experiencing dizzy spells (what type of vertigo

was it and why was it happening? Was it a virus, a cold, or was it an underlying symptom to a bigger problem?) The dizziness alarmed me, because I had problems with my ears as a child and thought maybe I was experiencing the same problem as an adult. My hearing seemed muffled and over time, I just thought that this was how I was hearing. (This was the first time I had been to an ENT in quite a number of years). The doctor cleaned out my ears, and ordered an MRI to rule out if there were any other neurological problems that could be causing my symptoms. Dr. Orquiza also noticed that my inner ear membranes were weakened and slightly bowed in, and attributed this as part of the problem. It was on the MRI taken in early February 2006 that first showed that I had a 7mm radiographic Chiari Malformation. (7mm of right cerebella tonsillar ectopia) was how it was noted in the report.

In the meanwhile, I was given a prescription to take for the vertigo; it helped a little but was not a resolution to the problem. Tubes were eventually put in place in both ears and for a few weeks after, I felt a little better but overall still didn't feel right. Six months later, the tube from my left ear, fell out that not only caused the tube to make a big whole inside my ear but also caused the vertigo to occur daily, along with other symptoms to occur steadily rather than in episodes like before. As a result I had to have a procedure that is medically termed a right tympanoplasty. It is a procedure done under general anesthesia to patch a hole in the ear with Gel foam. A hearing test prior to the surgery showed that I had a significant conductive hearing loss.

How did your symptoms impact the quality of your life?

Symptoms at this point just spiraled out of control and my absence from work became more and more frequent. When you are not feeling well and a condition is working on you, it can affect every part of your life. I went to three different neurologists and they all said that it wasn't anything thing to be concerned about.

In March of 2007, I was referred to a neurologist and was reassured that this doctor will listen to me and take the time to diagnose what is wrong and get me to the place where I need to go if necessary. I met with Dr. Hefferan, and at that appointment, gave him the MRI and explained everything. Dr. Hefferan, after a very thorough examination, confirmed that I did have a Chiari 1 Malformation and that the only way to

cure the malformation was to surgically remove it. He also explained what Chiari malformation was and said that I needed to be seen by a Dr. Milhorat, who was a doctor in New York who specialized in structural malformations of the brain. Dr. Hefferan felt I was in distress and needed to be seen ASAP, that by the day's end, I had an appointment to be seen at The Chiari Institute (TCI) the following week. This experience has shown that sometimes it takes just a little extra help from a Dr. who cares to get you ahead of the line. It has also helped me to realize that we as patients need to be our own advocates and how important it is for each of us to keep pushing ahead, until you find the right resources that will help you in the long run.

How did you go about getting properly diagnosed?

The initial appointment at the Chiari Institute is set up as a two day outpatient visit. The first day I was evaluated by a neurologist, given a very lengthy and comprehensive medical history intake from a nurse and filled out paperwork. This intake covered medical questions pertaining to my birth, infancy, early child hood, education, adolescence and adulthood. It is one tool that helps the Dr's to specifically diagnose the structural malformation that you have.

It is very helpful to have a support system of at least one or two people with you when you are going through this. My mom, Paul and Anthony (two brothers) and I have gone through this together as a team. Mom in particular has been there when I was at my lowest, when I was scared, the one who took the brunt of when I was feeling my worse and made it possible for me to recover the way that I did and got to where I am now. I love you mom, Paul and Anthony. Thanks for everything. They each did their part, in helping me each step of the way. They were there before surgery, during my hospital stay and after I came home to recover.

This intake was a learning experience for me. Some of the questions about my physical traits that I always knew I had were surprisingly related to Ehler's Donlas Syndrome. EDS, is a genetic connective tissue disorder in which the collagen, does not function or work properly and causes you to have hyper-mobility in your joints. I.e. .As a child I was always double jointed but never thought it was an issue. I remember it being very easy to sit in the lotus position and with ease could get up on my

knees, walk on them, in addition to laying flat on my back and front while still being in the same position. I fit the classic EDS type, in the fact that I had a lot of physical “growing pains”, as a child. I am hyper-mobile in my fingers, hands and knees.

The second day I underwent a lengthy series of MRI's and X-rays which are common procedures for new TCI patients. Specifically, I had a 3D Cat-Scan, an MRI of the brain, Cine, cervical Spine, thoracic spine and Lumbar Spine. In addition, I had an x-ray of my cervical spine, in flexion and extension views. After the tests, we waited for the reports and headed back to TCI where I met with Dr. Bolognese, for the first time to discuss the results.

You should know if you are allergic to any medicines, before going for your tests.. A few of the scans that are ordered require you to have an injection of 3D dye. Not knowing I was allergic to the medication, the next day I broke out with red itchy blotches all over my body. To relief it, took taking steroids and anti-itching cream. It was a stubborn rash that was combated by the CSF (cervical spine fluid) that had built up inside my body.

Dr. Bolognese, during his consultation, explained that I did have a mild Chiari malformation but the tonsillar herniation was not the real cause of my symptoms. At the time, he was not sure what the one exact problem that caused the hernia ion. Dr. Bolognese ordered a stand up MRI, to be done prior to the next visit, to determine the exact cause. It was determined though that I did have Ehler's Danlos Syndrome. Dr. Bolognese went on to explain that there were two types of Chiari Malformation patients, associated chiari and True Chiari. He went on to explain that my tonsillar hernia ion was mild and was associated with or was caused by Cranial Settling. Cranial settling is when the skull sits too low on the spinal cord and this was not good.

What Surgical procedure(s) did you have done?

April 11th I went back to see Dr. Bolognese and it was the day I found out my complete diagnosis and the day he told me that I was a candidate for Cranial decompression and fusion surgery. I knew this was going to be a big undertaking when Dr. Chan informed me that the surgery was a big deal and that it had its risks. He also mentioned that my history of scoliosis had, put me at a greater risk for developing these problems. I felt assured that this was going to work because both Dr's said it

had a high success rate but was still risky. My true motivator was that I had to get better, no matter what it took. I remember feeling relieved that finally we had gotten somewhere and had gotten answers. At the same time, I felt overwhelmed by everything that Dr. Bolognese was telling me. Though, in the beginning I didn't understand everything that was going to happen I still felt positive with going ahead with this surgery, because I was in the best of hands.

In the interim of my surgery date, I unexpectedly had to take a medical leave of absence from work because my physical condition worsened which made it extremely difficult to function at a normal level. I had an episode where my legs gave out on me and I fell right down on my knees. I tried to get up on my own but couldn't. When this happened, I just gave up and took the advice of my neurologist to stop working and surrender to my illness. I could not do it any longer.

On May 1st I underwent all the pre-operative testing that is required by North Shore Hospital. The following day, on May 2nd, I was admitted into the hospital and had an **invasive cervical traction procedure**. I was put to sleep under general anesthesia and when I woke up, in the operating room, I felt like I was in a bird cage the way my head was suspended up by a halo traction device that was anchored in my head. Dr. Milhorat was very, very nice and like Dr. B, made me feel very comfortable. My head in traction, when Dr. Milhorat pulled up on my head with weights at 25 pounds all of my symptoms disappeared. I could not believe it, the pressure in my neck and the headaches were gone. This procedure proved positive that I had cranial settling and I was headed for Cranial decompression and fusion surgery the next morning.

It was May 3rd and at 6:45 am in the morning I gave my mom a hug and was wheeled to surgery. When I was on the stretcher, I was getting nervous just watching everything that was going on in the operating room. The holding area was in the hallway right outside the Ors equipment room. Seeing all the sterilized boxes and what was involved with the surgery really put me over the edge emotionally. My fear watching this didn't last long though, because I was so tired that I closed my eyes. The surgery initially was going to be four to five hours. However, Dr. Milhorat came out at one point during the surgery and spoke to my mom. He told her that there was more work they had to do than expected. He explained that my

cervical spine was like a zing -zag and in bad shape. The Dr's had to straighten, reconstruct and decompress the vertebrae from c1 to c7. The second part of the surgery was when they fused my head to my spine.

After the eight hour surgery, I spent two days in ICU, until I stabilized. By the third day I had stabilized enough to be moved to a room on the regular floor. I don't remember much about these three days, only that I felt like I was run over by a truck and that my head was shaved. I also felt as if someone had taken my head and wound my head up as tight as it would go. I pull no punches here, the pain was really bad but the nurses made me real comfortable by administering strong intravenous pain management drugs..that were controlled by the doctors. All I had to do was push a button whenever I needed something for the pain. Altogether I spent seven days in the hospital. It is humorous to think about now, but when I woke up, I was surprised to look down on myself to find a grenade type drain attached to me. They used this drain in my head to help drain out any fluids that built up in my head from surgery. The physicians' assistants were wonderful in explaining things to me. One thing to note is that not every patient that has decompression surgery is handled the same way. Every patient is treated in their own special way depending on its own circumstances and specifications. Getting out of bed and moving about was difficult and definitely a challenge, for me. I found it helpful though to use Yoga type breathing to cope with the discomfort. I did everything at my own pace. A physical therapist evaluated and worked with me and was given a walker because I had difficulty with walking and had other neurologic weaknesses.

What was the recovery like and what is its duration time?

The complete recovery time for decompression and fusion surgery is one year. The recovery happens in stages and it takes time for the brain tissues and bone to completely fuse together and for all the swelling to go down. For every ½ hour a patient is given anesthesia, it takes one week for the body to rid itself of the toxin.

When you are discharged from the hospital and are ready to go home, you are given a one month prescription for a narcotic pain medicine. However, because the prescription is a controlled narcotic drug, it can only be filled at a pharmacy that is contracted

with North Shore Hospital. It is recommended that you find a pain management specialist in your own area to follow up with during your recovery. I strongly suggest finding the appropriate Dr. ahead of time, before your surgery. I consulted with three different doctors, before I found one I felt comfortable with. Thus some PM physicians only treat patients who are trying to prevent having surgery. Many Dr.'s like Dr. Yu are also trained and experienced anesthesiologists. Once a month, I had an appointment with Dr Yu to change and regulate my medications, and to consult with him about any post surgical symptomatic pain I was experiencing.

In November, I had a nerve block procedure to help deaden the sharp needle point pains I was having in and around the occipital nerve area of the brain.

Physical therapy exercises were continued at home and then in July, I went to physical therapy three times a week for 3 months after surgery .For the first three months, the recovery was slow and at times very uncomfortable. I just concentrated on controlling the pain and was in bed most of the time. It was the convalescent period and this was expected..You start very small and slowly graduate to the next level of the recovery. Each month gets a little bit easier as my brain went through stages of the healing process. I did not know what to expect and was not told what was considered normal because .not everyone who has this operation experiences the same exact side effects. Typically, the brain and spine become swollen from surgery for a good three months and as a result can alter a few of the bodies normal functioning. During the convalescent period, I just allowed my body to heal and allowed its functioning to return to normal. Sneezing, going to the bathroom and yawning were almost nothing and stopped for awhile.

What differences have you noticed since surgery? Are there things you can do now that you could not do before surgery?

Since the surgery, I have experienced the relief from pressure headaches, major muscle aches, dizziness, and have not had one episode of asthma. I have also noticed a gradual progression of my strength and stability, resulting in improvements in walking and standing.

Did the surgery cause any limitations?

There are a few limitations that the decompression/fusion surgery has caused. The fusion involved putting in a multiple number of screws and a metal plate in place at the base of the brain and c-spine. This procedure is done to establish stability and new positioning of the head and neck. As a result, I have lost about 80% range of motion in my neck but have found ways to compensate for this loss of movement. Part of my physical therapy has been to focus on strengthening and training my eyes and upper body to do the work that my neck cannot. I have also learned to move my upper body as a whole to compensate for the movement I have lost.

Another limitation is I can no longer hyper extend my head and do things that will cause jarring of the head and neck. I.e. jumping, making quick turns, going on roller coasters, doing high/low impact aerobic and yoga exercise, arching of the back, and most important, I cannot drive or travel in a car without wearing an aspen collar. To make driving easier, I have installed a wide rear view mirror and two side view mirrors, in my car. These mirrors make it possible for me to see my blind spots and side views without having to turn my head.

In addition, I have had to get use to new normal sensations in my head. I have had to adjust to the pain free but sensitive feeling at the base of my head, because of the two screws that are there and can be felt.

What is your quality of life like now, after surgery?

In September I returned to work and at first I saw this as a challenge. I was not sure if it was the right thing to do but did not want to risk losing my job. I was still on pain medication and did not know if I was strong enough physically to handle the demands of a teacher's aide working with children. In the end, going back to work and slowly resuming every day activities, proved to be the best medicine.

Today, I am off pretty much all of the pain medications, and am only taking flexoril and extra-strength tylanol.

The quality of my life has definitely changed for the better. I am now a healthier and happier person than I was before and now I can focus on other things in life. I am continuing my college education part-time at Kean University to earn a bachelors degree in elementary education and to pursue a career in

teaching.

In closing, remember that you are not alone and there are people who know what you are going through and have been where you are now. There is strength in support. I welcome all positive comments and any and all questions that you may have.

Christine@marchesano.org