## My Husband Has What?? by Brenda Franco

What happens to the wife of a man stricken with this hard to understand condition? Less then two years into our marriage, the week of Christmas 2001, my husband very calmly asked me what time I would return from Christmas shopping. I laughed and made some remark about when the money ran out.

He didn't laugh. Then I noticed that he had the oddest look on his face. He asked if I would take him to the hospital when I got home. Jes is a man who doesn't go to the doctor unless there is something very wrong and I knew that he was in some kind of trouble that was not yet apparent to me.

He described pain throughout his left side and neck and believed that he was having a stroke. We spent 10 hours in the emergency room where after exhausting tests they told us that they believed, even though some of his symptoms didn't fit, Jes had indeed suffered a stroke. There was nothing to do but take him home and see a specialist in two days.

Stroke is a scary word. But what was about to come our way was life altering! With every passing minute I saw my husband grow worse. Pain traveled down his body and he lost feeling and control over his left side.

The specialist we saw suggested that a correct diagnosis was not a stroke but Multiple Scleroses. Again, I took Jes home. I searched the Internet to learn about MS. The more I read the more I knew that this wasn't it! Jes was getting worse quickly and I needed help!

Our family doctor had just closed his practice and I began a frantic search to locate a new physician who would take Jes and see him quickly. With the help of a friend we had an appointment within 24 hours with a man who listened and agreed that Jes had not had a stroke and did not have MS.

I watched, unable to help, as my husband seemed to worsen with each passing hour. He was in constant pain and unable to walk or stand unaided. I was so scared. My once strong, dependable partner became weak, confused and frightened. What was this? How could we save Jes? What was this going to do to me?

Finally, after an MRI a correct diagnosis was made. We were told that Jes had a large syrnix running the length of his spine that was filled with fluid. He had Syringomyelia. Our Doctor told us that he wasn't familiar with this condition but he knew that Jes needed help right away. He made some phone calls and recommended a specialist at Shands Hospital in Gainesville, Florida.

Arrangements were made for Jes to be seen within the week. In the meantime, while my husband was in an almost constant drug induced sleep, I searched the Internet to arm myself. Our monster now had a name - Syringomyelia.

I read everything I could find, but nothing told me what the future was going to be for us. Nothing really gave me hope. I don't think I have ever felt so alone. My friends couldn't help because they didn't know anything about Syringomyelia. Jes and I were going into battle on our own.

We were on the road two days later. The trip from our home to Gainesville was hard on Jes. He was in so much pain that every bump in the road was agony. I wanted to get there as fast as I could to deliver him into the hands that I hoped would heal him.

We met with the specialist the following day and were told that we shouldn't count on Jes ever regaining what he had already lost as his nerves had already been damaged. His plan was to try and stop Jes from worsening. There would be a shunt installed into Jes' spine to drain the building fluid and relieve the pressure. The Doctor explained all the risk associated with surgery of the spine. Then he left the room.

Jes and I just sat in silence for a minute while all the words soaked in. How could he not get better? How could this be as good as it was going to get? I saw the tears that Jes was trying to hold back and knew I had to do something, say something. I quickly spoke up. We agreed that this doctor had no bedside manner. There was nothing comforting in his speech. We knew that he was the best available and that there really was no other choice. Surgery was set for the following day.

My mother-in-law and sister-in-law came to the hospital and I was glad for the company. Being alone with my thoughts was not a good thing. My mind raced trying to solve all the what ifs and a "why us" refrain kept echoing in my brain. The morning of surgery these normally strong ladies entered the chapel and fell apart. This was their son and brother. They had known him his whole life. I was the new wife and I found myself feeling like I was an outsider as they clung to each other. But I knew what was really important. It was that Jes had a lot of people who loved him. Then I prayed.

Surgery took place on January 18, 2001. As I sat trying to remain calm in the surgery waiting room they paged me to take a phone call. The message was that the surgery was going to take longer than anticipated but we shouldn't worry. The procedure was more difficult then anticipated and there were some problems with Jes's breathing during the procedure. How could I not worry at this news?

We had been waiting for hours when a nurse came and asked me to come with her. A wave of panic swept over me as I followed. I asked where we were going. She said the recovery room. Now during the pre-op briefing, the doctor had been very specific about telling me that we couldn't see Jes in the recovery room. We would see him once he was settled into intensive care.

At that moment I believed that Jes had died and that she was just getting me away from all the other people in the waiting room to tell me.

We exited the elevator in silence and as we turned the corner and entered the recovery room my legs felt weak and somewhere deep inside I was screaming. There was a curtain slightly pulled aside and I saw Jes. There was blood on his head, face and chest, places I hadn't expected it. I just looked at him. Then he opened his eyes.

I got to kiss him quickly before they ushered me out. They just wanted me to see that he was okay. The blood was from a halo he had worn during the surgery. It would be hours before I could see him again but at least I would see him again.

I don't think Jes had any idea of how much pain there would be. He is one of those macho guys who is tough and suffers in silence. What bothered him the most was the fact that he was so weak and so dependent on me for even the smallest things. I became the person he had to lean on.

During his hospital stay, Jes was treated well. He spent four days in intensive care and another 6 days in the surgical ward. Then they released him into my care.

We heavily medicated Jes for the ride home. Even in his sleep he moaned as he shifted trying to get comfortable. He was helpless to do anything for himself. There was an eight-inch incision starting at the base of his neck that had to be kept clean and dry for ten days until the staples could be removed.

As I drove, I thought about everything I needed to do: make follow up medical appointments, set up physical therapy, get his prescriptions filled right away, keep his spirits up and keep him as comfortable as possible.

Suddenly, my life became overwhelmed with reality. I knew that Jes was going to be out of work and there was no way to know if or when he could go back. He had just had extensive surgery and a ten-day stay at a major hospital and I had no idea what our final bills would be. I knew that I was also going to have to be the one who kept us afloat. My job is in commissioned sales, so I knew I had to stay focused, push harder- whatever it would take for us to survive economically as well as physically. I took a deep breath.

Jes could no longer lie down, so we set up a recliner chair in the living room and that became his bed. For the first week at home he slept most of the time. He was discouraged that he still had no control in his left hand, arm or leg. All he had were muscle cramps and constant pain. I kept wondering if he was going to be ok with his new limitations. I wondered if he would fight back or just give in.

Physical therapy was a difficult mental challenge for Jes. He was literally reduced to taking baby steps as he struggled to regain balance and willed his left leg to walk. For a man who has spent all of his life actively playing team sports, recovery became his strongest opponent.

His incision healed well and we just kept waiting for any small sign that life would get back to normal. Weeks passed and there was no improvement in Jes' condition. Jes' doctor decided to order another MRI and scheduled a follow up trip to Shands.

The next day I picked up the films and report and opened it in the parking lot. Even I could easily understand what it said. Syrnix still present. No improvement seen from prior MRI. Shunt is present. I cried for Jes. I cried for me. I cried for us. Now what?

I didn't tell Jes what I read. I put the films and report in the trunk of my car and went home to get ready to head to Gainesville the next morning. I was aware that I was to quiet on the drive. My mind was racing and I couldn't make small talk. Luckily, Jes slept most of the way. I was hoping there would be another answer. I had read articles that made shunt surgery sound like a last resort. So now what were our options?

In the doctor's office I held Jes' hand as the MRI films were snapped up over the light panels. The doctor shook his head and told us it didn't look good. The surgery had failed. Just like before, he left the room. Jes looked at me and asked if I had known. I told him yes. He had known too. We just didn't want to say it out loud. It's like if you don't say it out loud then it won't be real. But it was.

After a few minutes the doctor returned. Jes asked where we go from here. The only option offered was another surgery with a shunt placed into the lungs. We couldn't make any decision right then. We needed to be where it was safe. We wanted to be in a place where we could deal with this privately. So I took Jes home.

On June 1, 2003 Jes underwent his next surgery. At least we knew what to expect. After another hospital stay, we came home. Jes was settled back in his chair and we waited to see what the outcome would be. It's a terrible thing to say but I grew accustomed to sleeping alone. But I never got used to waking up without him in the morning. That's the hardest part. When you're just waking up and you remember.

Syringomyelia has robbed me of the comfort of my husband's arms around me. The hardship for me is that I remember too well how it felt to be with him. I see a longing in him too. It's another subject that we never discuss out loud. It's as if we wait for time to diminish the passionate memories. He has his constant pain and I have my constant frustration at not being able to fix him.

After a few months the second surgery was deemed successful. That doesn't mean that Jes will ever be better. He will never have feeling on his left side. Nor will he ever have full control. He can't stand to be touched most of the time because the pain is so excruciating. One half of him freezes while the other side sweats. He has to be helped with the simplest tasks.

Jes remains prideful and defiant. He is frustrated daily and he hates what he has become. He has told me to leave him because he feels that he is no longer the man I married. I guess that I've become more a caretaker than a wife. I wonder if that's how he sees me as well. I'm afraid sometimes that he resents me because I am still able-bodied. I know that he is concerned and jealous because my job is a social one that often involves lunches and occasional evening meetings.

There was no one to tell me what it would be like when your spouse gets Syringomyelia. There was no one to tell me how to cope- no one to tell me that it's okay to be angry. I spend so much time taking care of Jes and worrying about him that I know a part of me has become lost too. You see, my husband may have Syringomyelia but we both suffer with Syringomyelia.

If anyone asked me what it's like to be the spouse in this medical crisis, I would tell them how quietly I lay every morning praying to hear breathing coming from the living room. I would tell them how it breaks my heart when I see defeat in my husband's eyes after he loses his balance. I would tell them how hard it can be and how alone it can feel.

Most importantly, I would tell them how wonderful it is that Jes still has his quick wit. How he continues to make me smile. How much he loves playing with our little dog. How happy he is when he's out on the deck staying dry while it's raining. How much joy he finds in screaming at the television if the Red Sox aren't winning.

I guess that my point here is that there is a lot to be sad about. We have definitely suffered a loss. But there is so much to be thankful for too. We know that Jes could have been stricken with something that robbed him of his mind. So as odd as it sounds, we'll take Syringomyelia. Hopefully, we'll continue to take it in stride.

Would you like to share your perspective? Submit to: director@conquerchiari.org Type "Perspectives" in the subject line.