A Parent's Hope, by Kathy Moloney

Ed. Note: *The opinions expressed below are solely those of the author. They do not represent the opinions of the editor, publisher, or this publication.*

Another summer has passed and it is back to the school year for my daughter Megan. The summer has gone so well for her and she has been feeling great. Although I try to convince myself that maybe it will stay this way, I am learning to not take it for granted. Megan has syringomyelia. I still have a hard time pronouncing the word but I have learned its meaning first hand.

Megan is a bright, beautiful and talented 13 year old girl. She has always tired easier than my other two daughters but it never occurred to me anything could be wrong. Megan has her own horse, and rides everyday. She has for years. She is the picture of strength. He is a large horse (17 hands) and is not easy to handle. Megan competes with him jumping and has three counties of championships. Ribbons, trophies, and other prizes cover the walls of her room. I thought that perhaps she was riding too much, and that was the reason she was feeling more tired than usual. My world was about to change forever on January 10th, 2002 on her 12th birthday.

I always felt Megan was the lucky one of my three daughters. My oldest had been premature and learning disabled. My middle daughter has severe dyslexia and been diagnosed with a venous angioma in her brain. She was born with it but we did not know till age 10 when she started with headaches and I took her to a neurologist. My biggest worry was that it would someday grow and they would need to do surgery. Imagine- brain surgery for your child, how scary is that!

When Megan started with headaches, my pediatrician told me it was migraines. After months of her complaining about these headaches, I decided to get a neurologist to have an MRI done to appease myself that nothing was really wrong. I remember that winter day we went for the test. I stayed in the room with her and rubbed her feet while the test was done. Poor Megan, I thought I was such a neurotic to put her through this. I listened to what sounded like tribal music pounding in the background for over 2 hours from the MRI machine. I felt guilty that I pushed the issue to have this test done. I knew nothing serious could really be wrong and worst case scenario she would have the same thing as her sister. We would monitor it and that would be it. Then, the noise stopped, the door opened and a man whom identified himself as a medical doctor told me I needed a neurosurgeon - now! They wrote the measurements on a piece of paper and I remember thinking and trying to process what I would need a neurosurgeon for. I only brought her for this test to make sure nothing was wrong! Instead, they told me to use the phone on the wall and call my doctor immediately. I called the neurologist with the measurements of Megan's "syrinx" (11cm x 9cm). What a syrinx was, I had no idea but I knew it was a MAJOR problem. They made that very clear.

I left the office with Megan and tried to stay calm. I did not want her to know what it meant. I was crying while I was driving so I am sure it made her nervous too. I was afraid to have her in the car - like she was an egg about to crack. I assured her it was like getting her tonsils out, and maybe they could not do anything at all. I remember comparing it to that since several of her friends had gotten their tonsils out and I thought she could relate to that. I tried to make it like it was no big deal. Inside, I was in complete panic. All I wanted to do was go home and search the internet.

The next morning my husband, myself and Megan were sitting at NY hospital in front of neurosurgeon, Neil Feldstein. Still unsure of why we were there, I was still hopeful that he would tell me something different. He put up the films and showed us how compressed Megan's spinal cord was from the syrinx. It was from a Chiari Type 1 Malformation. There was so much pressure on her spine they thought it was about to snap, which could paralyze her. This child was bouncing on a horse everyday! Why and how could this happen? Unfortunately, there was no answer. We just wanted her "fixed". Surgery was not an option, but a necessity. The surgery was done within three days. They let us stay with Megan until she was under anesthesia. I could not imagine not being there with her when she went under but the feeling was so surreal. I was just thankful they gave us a mask to wear into the O.R. so she could not see the expression on my face. I could actually feel the color draining from my skin as I looked at her on the operating table. I did not want her to know how frightened we were for her. All I could think of was "Thank God I have the mask on." We tried to make it playful and took some photos of her with her hospital gown on and ready for surgery. Each time I snapped the photo I remember thinking it was almost morbid to do. It was such a relief to know the surgery was over. I thought that would be the end of it. Megan would feel better and we would go on like before. Instead, her pain was horrible. She had a morphine pump. It was not enough to relieve the pain. The hospital stay was a constant staring at her to make sure everything was alright. We came home for what seemed like the longest car ride. Every pothole on the FDR was magnified on her body. She felt every bump in the road. When we were home and it was time to help her bathe, I was afraid to touch her hair that had the blood still in it from the surgery. The back of her head was swollen and mushy. Her balance was off, she needed help to walk. She was very weak. Her head looked like a baseball glove from behind the way it was stitched. The doctor told me to call if I saw any clear fluid coming down the back of her head, that it would be cerebral fluid. I was afraid the cerebral fluid would leak. I was afraid of everything with her. I would sleep with her since I was afraid she would roll off the bed. It was horrible to watch her go through this. I did not feel qualified in anyway to have taken her home after five days and care for her. I felt useless if there was an emergency and being 2 hours north of NY Hospital in a rural area did not help much to relieve that fear. She suffered throughout the healing process and slowly, she regained her strength. She could not wait to ride again. It was what she talked about during the healing process. I kept hoping she would change her mind, stay home forever and not do anything that might jeopardize her! I was sure the doctor would agree and I thought he could be the one to tell her no. The riding issue was to be put to the side for now.

I was so sure at the three month checkup that the MRI would show it was all gone. I made the mistake of being excited. It was still therebarely different by one millimeter. I was assured the pressure was off the brain so her spine would not snap, it was just going to take a little longer for it to reabsorb. I was sure we were going to look at the next MRI series and it would be gone. And the next, and the next and then the heartache really came when I saw the results eighteen months later and 70% of the syrinx was still there. A sad reality to the situation I thought.

There is a guilt that goes along with all of this. Although I ate right, did not smoke or drink during pregnancy, I was on medication. I did not know I was pregnant. I had continued to take my birth controls the first six weeks of pregnancy because I did not know they were not effective from the antibiotics I had been taking for a bad chest cold. Then there was the premature labor at 24 weeks with Megan and the medicine that I was put on to stop it which was later pulled from the market. It had been used to sustain my pregnancy early on. I had been given it several times in the hospital intravenously to stop the early labor so her lungs could develop more. Could any of these contributed to the Chiari? I am sure I will never know. It would require years of research to ever conclude something like that. If I were in the same position again, I would do the same to preserve the pregnancy. NO one knew there was a problem until she was 12 years old. I do not blame my doctor or anyone else for anything they gave me to keep the pregnancy going. I am forever grateful to them and the medicines that made it possible for her to be born. I will always wonder why this happened and if something I did caused it.

Not a day has gone by that I do not think about what has happened to her life. What it may mean for her future. What it means for mine. She has goals. She wants to be on an equestrian team. She sees the glass as full. I have to respect that. I used to watch her ride with great pride the way she handled her horse. She is a gracious rider. She is truly at ease on her horse. It takes her to a place I could never go. She enters her own world with him and only she has the key. Every time I watch her ride, I now sit nervous, afraid she will fall. I sometimes do not like to get too close to the horse as I am afraid he will sense my fear. My fear might make her fall. I wait for her to finish her jumps in competitions so I can feel relief that we have gotten it over with - the thing she loves to do.

Her neurosurgeon tells me to let her ride. I gave that a lot of thought. She now wears a safety vest which is very much like a bullet proof vest to protect her spine along with her helmet. I believe the glass is ½ full and that is with hope. But I do not tell her that. Who am I to ruin her dreams? I am learning that syringomyelia can define you or it can be a part of you. If you let it consume you, it will. If you fight it, it may still consume you one day but at least you tried to live you dreams. While she is young, I want her to do everything she can. I do not know what this syrinx will bring over the years but I am told there is a great possibility that it may not get any worse. I hold onto that. Every day she feels good is a great day. The days that she does not feel well are "rest" days. Heat packs, ice packs, massages, physical therapy, and our tens unit - our survival kit.

I find over time, people think that this is over and I think they forget about it. I want to forget about it but that is not an option. People do not ask questions, perhaps because they do not want answers. When I say that Megan is not feeling well they seem surprised. How can people be surprised? Did they not hear me explain what syringomyelia is? What it does? Do they think because they do not see it that it is not there? I find that very few people want to know about those dark days. I have tried on-line support groups but I find them depressing. No one seems to be positive. How can they be in a world full of pain? I cannot accept that world for Megan. I still hold on to the hope that next year's MRI will show improvement. I just keep putting us in this little bubble of hope that it will all just go away. Maybe she will be the lucky one. Maybe when the weather changes in the next few weeks she will not react to the cold like she did last year. Maybe, maybe, maybe…

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