

The Greatest Joy

Our son Stephen (12 years old) was diagnosed with Chiari Malformation and Syringomyelia in October 2004. He was suffering from weakness of his legs, migraines, upset stomach. I think we were very fortunate, because our family doctor took seriously my complaints of what was going on with our son. So she ordered a series of MRI's.

Of course with all other parents of children that get this information...you don't know how to react because in most cases, you have never heard of it. We were set up with an appointment to see a Neurosurgeon and he gave us the news. Our doctor's assistant told us to get on line and do research. I came home and started right away. Everything I read, terrified me. My doctor, is a great doctor, didn't give us a lot of information about this. He did explain what was going on, but maybe it was where you are just so numb, you have a hard time taking it all in.

The doctor wanted to wait another 3 months and do another series of MRI's to see if there was any change. In 3 months, we came back and there was a big change. So he arranged to do the surgery in 3 days (Jan 2005). That was so we could get things cleared with our insurance. He did a Posterior Fossa Decompression with Duraplasty with the operating microscope. The surgery lasted just around 3 hours. Stephen was in the hospital for 4 1/2 days. He was in PIC for 2 of those days.

He had struggled with getting his strength back, but he had next to no pain at all. In fact, after he got out of PIC he just took tylenol for his pain, and then he just had to have it once in a while. He has done great. He was out of school for almost 3 months, but the school worked with us and when it was time for him to start going back to school, they let him go half days and then to all day. This week is his first full time back. He still gets tired, and gets weak, sometimes has headaches and stomach gets weak...but that is once a week maybe and it isn't all the pain he had before. But before the surgery, it was every day and it was bad. He just had his first MRI done since his surgery and his syrxinx has shrunk some. That is great news!!

Next week, he will be able to play again with the other kids and start riding his bike. The doctor said that his neck has pretty much healed but it will take close to a year for the spinal cord to heal. But to see our son smile again...that is just the greatest joy. We do have a great doctor...he is so great with our son...making him feel at ease. That makes things much easier also. I'm sure this will be an ongoing process, but you take one day at a time.

Sharra Hughes
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