

Deciding What Is Right For Your Child | September, 2005

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. Anyone with a medical problem is strongly encouraged to seek professional medical care.

By Mary

My son, Vinnie, was recently diagnosed with Chiari Malformation I and Syringomyelia, I personally never heard of it before that. He is a healthy, vivacious seven - year - old boy, we found this by having a MRI after he bumped his head. He had an odd headache now and again; the only reason it was cause for concern was that it was always at the back of his head. Having only boys, bumps were bound to happen, but this headache was not really something I had seen before and it pushed us to have a MRI. I didn't worry at all thinking the MRI would be normal. Of course, it is good we know now what we are dealing with but now that we know we have to deal with the situation.

First off, we were referred to a neurologist and neurosurgeon at our hospital for an "abnormality" found in the MRI. What does that mean? No one can tell you before the specialist appointment, even Vinnie's pediatrician wasn't sure or familiar with the reason. When we finally saw the neurologist she explained it to us, we were shocked, scared and confused. She wasn't sure if our son was born with the Chiari and the Syrinxes have formed since or if he was born with it all. Her thoughts were that Vinnie should be monitored with MRI's and carry on. But we were referred to a neurosurgeon that seemed to be the protocol. At the end of the appointment, we went away thinking we will go to see the neurosurgeon but hopefully my son will not need surgery. After all he has no symptoms, the headaches could not be classified as symptoms for sure, and he is healthy, athletic and happy.

About a month later at the neurosurgeon's appointment we were told my son did indeed need surgery, definitely, not emergency but preventative surgery. My son asked the doctor does he need to have anymore MRI's because he hated being put to sleep and then waking up with that annoying and hurtful IV in him. The doctor told him you don't need another MRI, because you will be having surgery. My son was happy of course because he doesn't know what the heck surgery is. I left feeling shocked, sick to my stomach and more confused. My husband on the other hand wanted to schedule it next week; he thought it has to be done. I said I wanted to think on it and maybe seek another opinion because I felt at this point; we had already received two different opinions. My husband wanted it done in case of anything happening and making things worse, and school was about to start up again so he wanted our son to be in and out of surgery and all ready for school. I felt like a whirlwind was about to hit and I had to sit and think for a bit. I couldn't just go on with it all that fast.

My next step, putting my husband on hold for a while, was that I contacted my medical provider and they agreed to pay for an outside second opinion. (I would have done it either way.) We again saw a neurologist and neurosurgeon brought all the reports, health records, radiologist reports, MRI's, questions and my son. The neurologist asked all the same questions, did the same exam and said he felt surgery was not needed at this time. He didn't mean never just not while my son wasn't having symptoms and due to the findings of the MRI, in his opinion. He thought the Chiari was not that "far down" and the syrinxes were thin. I was delighted we agreed, "don't fix what is not broken!" But we still had the neurosurgeon to see, he was highly recommended from medical professionals I knew. It did cross my mind would it be like *deja vu*, one conservative and one not. Do all Surgeons think surgery cures everything? (In the last few weeks I have contacted every person I know in the medical field and asked them to check into this and check with doctors/nurses they knew, as I searched the Internet. At times the Internet scared the hell out of me because I think they tend to lump all the symptoms together and make it the worse scenario so I have tried to seek out specific web sites. I was recommended www.conquerchiari.org by a friend and that was the most helpful I thought, it was like *Chiari for Dummies*. It was in laymen's terms with questions and answers not all medical jargon no one can understand.)

We then saw him, he agreed with the neurologist. He again did all the same neurological tests and saw all the reports and agreed with not having surgery. He said if it were his child he would monitor him with MRI's every 3-6 months. This just happened 2 weeks ago, I am happy but now very much confused. These steps take us time to digest one at a time. When I heard this diagnosis at the beginning I was in shock, now I am sort of in shock again, because if it was clear-cut we had to do the surgery then we would, no questions asked, but now I know it isn't and with surgery can come complications. Why put my little healthy boy through all that now at this time in his life if he is living a normal life. The last neurosurgeon we saw explained that the first one we saw probably wanted to do the surgery for preventative measures. The latter one didn't see anything wrong with this, but he doesn't practice that way, he likes to watch his patients over time with MRI's and visits to the neurologist. If any changes occur in the MRI or any symptoms arise then surgery. He thought the change would come in the MRI first before symptoms so we would catch it in time. I said what if I don't notice or Vinnie doesn't tell me of a symptom. That is why the MRI is the vital key in all of this. It could be 6 months, and it could be 6 years.

My next dilemma is how do I go back to my medical provider and tell the doctor, the one that may one day do surgery on my son, we've decided to wait on surgery. We have had a second opinion and now feel surgery should wait. I know all doctors are professionals and they all remind you of this, but I also know everyone is human and do not like to be second-guessed. I can't worry about that.

Now we are praying that we make the right decision for our son, one that keeps him healthy, and one that will be ok now and in time to come. I so want to take the conservative approach. Something inside of me is saying, "Maybe we need a 3rd opinion?"

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