

## More Thoughts On Deciding What Is Right For Your Child

**Ed. Note:** This story was originally sent in as a Letter To The Editor in response to last month's Perspectives, [Deciding What Is Right For Your Child](#). The author graciously agreed to have it published as a Perspectives.

Hi! I have been reading your web site ever since I found it when my daughter was diagnosed with a Chiari Malformation and syrinx. It has been very informative and helpful in my quest in getting the proper treatment for my daughter.

I recently read the article entitled, "Deciding What Is Right For Your Child." Like the author of the article, I too was faced with some very difficult decisions regarding my daughter who is also seven years old. It seemed to me that she would like to hear from other parents who have experience with what they are going through.

My daughter was diagnosed quite by accident. She wears hearing aids for mild to moderate hearing loss. We never knew why she had this hearing loss. It came to light after six months of ear infections that started at the age of three. After her six year check-up, her pediatrician suggested we may want to get a CT scan to see if we find anything. Her other physicians had never requested one since her hearing loss was determined to be nerve damage and not damage to the middle ear bones.

Since I am an MRI Technologist, I thought I would do an MRI scan of her internal auditory canals since there is no radiation involved. The owner of the company I worked for also wanted to see if a child her age could hold still for the MRI without sedation. I was able to do the MRI and to my shock I saw the Chiari and syrinx on the lateral scan.

I went through many emotions; shock, denial, grief and guilt. I felt I somehow must have done something wrong during my pregnancy to cause this malformation. However, it was a perfect pregnancy with no complications. Once I received the report from the radiologists I spoke with them and they all assured me it will be ok and that it doesn't necessarily mean surgery for my daughter.

I had consultations with several neurosurgeons and neurologists. Each consultation gave me more information than I had previously. I found it very helpful to talk to as many professionals as I could. Reading the [Conquer Chiari] web site also educated me on the disease and prepared me with the right questions to ask all of the physicians.

My daughter's neurological exams were all normal. She occasionally got headaches but I mistakenly thought they were associated with allergies. Since the diagnosis she started to get occasional neck pain, and weird pains in her back and shoulder. That is when it became scary. I didn't want her to have any permanent neurological damage. Once the damage is done, it can't be reversed. We decided to plan her surgery at the end of the school year so she could recover all summer.

With all the neurosurgeons I spoke with, one was a clear choice for me as her doctor. One of the key reasons being is that he had the most experience with treating Chiari in children. He did more Chiari surgeries in a month than most surgeons I had spoken with did in a year. The other surgeons were also not as positive with the outcome as he was. Because he did so many surgeries, his anesthesia staff was also used to performing the anesthesia in the face down position. He answered all of my questions and assured me she would do fine. He was right.

My daughter had the surgery in June. She was in the hospital for four days. She did great after surgery and she has not had any headaches or pain since. The incision is tender to the touch but I think that is because all of the nerves are waking up. We were very positive and honest with her about the surgery and what would happen. She was a terrific patient. She never cried even when they had to re-start IV's. I am very proud of her and grateful to her surgeon and God for the outcome we received. One thing I would suggest is for one parent to always be with your child in the hospital room. This made it easier for her and we were there for her when she needed something.

I know that parents are faced with so many difficult decisions with this kind of diagnosis. You want to make the right choices so that your child can live a happy, healthy life. Just don't put off the inevitable if it will help your child. Just make sure you are well educated and informed. Make sure you are 100% confident with your doctor and the support staff that will be taking care of your child. Don't be afraid to ask questions or get numerous opinions. You are your child's advocate.

In closing, I will be doing follow-up MRI scans to see if the syrinx will shrink or go away. I have heard they usually shrink or disappear over time. The worst case scenario is that it won't get any bigger. I will send you an update.

Best Regards,

Mrs. Rice

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

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