Asymptomatic Chiari, Good News or Bad?

The neurosurgeon's words were clear enough, "Your daughter has Asymptomatic Chiari."

The following is an experience, I fear, more and more parents with children who have a Chiari Malformation will have to endure as CM becomes a more prevalent diagnosis.

I wanted to share this experience with others so in the event they receive similar news from their neurosurgeon they are better prepared for the flow of mixed emotions which will inevitably enter their hearts. Additionally, the experience allowed me to understand more fully that watching your child grow up can be both a painful and unimaginably rewarding experience. (PS - While you read this please keep in mind I sometimes use humor has a stress reliever.)

Allow me, for a moment, to introduce my daughter Victoria. "Tori" as we call her is a 19 year old college student.

Tori was born with a meningoencephalocele (a little bubble filled with spinal fluid and meninges) located at the base of her skull. Evidently during fetal development her skull did not completely fuse together. So, on day three of her life Tori was operated on and a Teflon meshing used to seal the opening.

To the surprise of the operating neurosurgeon, Tori never required a shunt. And, with the exception of some dexterity issues and the unusual "mirror movement" disorder she has grown into a very bright, ebullient, beautiful young lady. (I'm the father I'm allowed to brag!!)

But recently Tori started suffering from migraine headaches and complained of intense pressure within her head. This led to the MRI exams which led to the initial diagnosis in January of Chiari Malformation with a 7mm herniation. (Which led me to the obligatory weeks and weeks of panic and scouring the internet for information.)

In March we had an appointment to see a neurosurgeon who came "highly recommended."

As Tori, her mom and me sat in the waiting room nervously anticipating our meeting with the neurosurgeon we reviewed the contents of a 3 ring binder I had put together. I had printed out just about everything I could find on CM. The binder was filled with printouts, diagrams, photos, articles, and surgeon recommendations. We also reviewed all of the questions we were planning on asking the doctor. (Knowing full well that in the stress of the examination room we'd probably forget to ask him most of them!)

We felt ready and armed with enough information and knowledge to insure we would ask our daughter's surgeon the right questions and, more importantly, we would understand what he way saying. We felt as prepared as possible and ready to grasp all the aspects of the Decompression surgery we were sure would be recommended.

"Victoria?" the nurse called into the waiting room. We all rose (more like jumped) and went in to see the neurosurgeon. With me, I carried the 3 ring binder, my "Chiari Bible", securely tucked under my arm.

Tori quickly exchanged her street clothes for the ever fashionable "backless medical dress" provided by the nurse. We then anxiously waited for the doctor to come in. After a few agonizing moments the doctor entered. I will refer to the doctor as Dr. "No", as in no personality or "bedside manner".

After some initial "how do you do's" Tori's examination began. First, she was asked about her migraines. "Do they start in the back and radiate to the front?" "What does the pain feel like?" "Are they brought on by sneezing?" "Coughing?" "Is the pain behind your eyes?"

During this questioning and without diverting too much attention from Tori he would matter-of-factly respond to our questions and other bits of information about Victoria we thought were relevant. (They probably weren't.) But, we just didn't get a very warm and fuzzy feeling about Dr. No. (As an aside and added insight into my nickname for the neurosurgeon: He made me feel somewhat reluctant to ask more questions after the 3rd time he corrected my pronunciation of some medical term.)

Understand, we didn't want to interrupt his examination of our daughter but we had so many questions and thoughts running around in our heads that we felt compelled to blurt out some questions just out of fear of forgetting to ask them altogether!! We simply needed more neurosurgeons in the room.

Next were some physical tests. Victoria was asked to squeeze the doctor's hands, walk across the room (a 8 foot examination room which took her all of 1 ½ strides to cross), follow Dr. No's finger with just her eyes, and react to pin pricks at various locations on her feet and legs, hands and arms. Victoria pushed and pulled against the doctor's resistance and then the examination was over.

As the examination and questioning of Victoria came to a close we all anxiously (a nice way to describe the fact that I thought I was going to throw up) waited for Dr. No's diagnosis and conclusions. He turned to Tori's mom and me and said blandly, "Your daughter has Asymptomatic Chiari."

Dr. No told us Victoria did not display sufficient symptoms to warrant Decompression surgery. In Dr. No's opinion the migraines may or may not be associated with the Chiari but he wouldn't operate. Almost immediately it dawned on us that we were being told we had to wait until our daughter felt worse before she could get better. At first this made no sense to us and seemed unacceptable.

"Asymptomatic Chiari" were not the words my ex-spouse or I were expecting to hear. (I'll write more about that "expecting" word later.) I mean, we knew Tori has a 7mm herniation. We knew Tori had suffered from migraine headaches and extreme feelings of pressure within her head. We knew the Cerebellum should not be situated where it was within our daughter's head. We knew that herniation often times results in Spinal Fluid flow obstruction. We thought we knew the neurosurgeon was going to explain to us how and when the Decompression surgery would be performed. Boy, were we wrong.

Now realize, Dr. No could have been (or for that matter be) the greatest neurosurgeon the universe has ever seen but as parents we still would have reacted the way we did. That's to say…….we didn't know how to react! We had prepared ourselves for getting details about Decompression surgery. We had "planned" our summer around Tori's operation and subsequent recuperation. Now, we were hearing news we weren't quite sure was good news or bad news.

Obviously we didn't want our daughter to have unnecessary surgery, for sure, but we also did not relish the prospect of not knowing when, if, or in what form the symptoms would manifest themselves. Could Victoria just collapse one day? Did the symptoms come on gradually or could they come on quickly? Do we spend the rest of our lives hoping she does not hit her head? What if she did hit her head? How could I make a helmet fashionable enough for my 19 year old to wear?!?

Unsatisfied, but unsure exactly why, we left the doctor's office and after a ½ hour of trying to find my car in the parking lot (a story for another time but it made Tori laugh so….) we went to get something to eat. Sitting at the restaurant, the mixed feelings continued. I wasn't sure whether or not to feel relief. I felt guilty I didn't feel like jumping for joy at the news that Tori's symptoms did not necessitate Decompression surgery. But why did I feel guilty? Why wasn't I perfectly content to assume Tori would be symptom-free for the rest of her life? (To make matters worse, it wasn't until after we left the doctor's office that we thought of all the "really good" questions we should have asked! Isn't that always the way?!)

We ordered breakfast and waited for our meals. As we waited Tori asked the question which makes a parent's Adam's apple feel like a cantaloupe; she asked, "Should I be scared?" Now, I don't care if your child is 4 or 40, when this question is asked you cannot help but take a deep breath and give thought to the best way to answer. Tori's mom and I looked at each other, blinked a few times and realized it was time to stop protectively weighing what Tori should or should not know about Chiari.

Tori was tenderly told she should not be scared but she should be careful. She was told that it would be a good idea for her to get as informed about Chiari as possible. She must be aware of all possible symptoms. Also, we suggested she become more cognizant of her body. She must pay attention to any "different" feelings or sensations she may (or may not) have felt a day, a week, or a month before. We suggested she keep a journal. I gave her my 3 ring binder "Bible Chiari."

As Victoria, wide-eye and unflinching, attentively stared at us (a la Cindy Lou Who from "How the Grinch Stole Christmas") I began to understand how much she did care about her health and well being. Maybe we had underestimated her capacity to "know the truth" about her medical condition? Tori could handle this. We had to trust her to monitor her own condition without becoming too frightened. We saw that our daughter, although not completely sure what was happening inside her head, did have a deep sense that despite having "Asymptomatic Chiari" and unsure what the future might bring, she was indeed more fortunate than many others.

CONCLUSION:

"Asymptomatic Chiari" never did cross my mind as a possible diagnosis. In all my research about CM I just don't recall reading a lot about or seeing a lot about "Asymptomatic Chiari". There is just not enough history on CM. In fact if you "Goggle" Asymptomatic Chiari not much information will appear. That fact alone will tell you how little is known about it. And that's the scary part, the unknown.

I had not been prepared to hear the diagnosis I heard that day in the neurosurgeon's office. I made the mistake of projecting and of having "expectations" of what I thought would be said. I now know that with something like Chiari, where there are much more questions than answers, it is foolish to get too ahead of yourself or have expectations.

"Asymptomatic Chiari Malformation" - Good news? Bad news? Only time will tell.

In the mean time we will seek a second and if necessary a third opinion. And I will continue to work on developing a bubble wrap body suit for all our beautiful "Asymptomatic Chiari" children to wear!

--*Bruce*

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