Perspectives | 10.05

Four Years Of Frustration

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.*

My son Isaiah was diagnosed with Chiari almost five years ago. It all started because he was having severe leg pain. Pain so severe he would sit still, hold his legs and cry. Occasionally he would have headaches. Always with the pain in the back of his head. Finally, after months of this he was seen by a Neurologist and had his first of several MRI's. With the diagnoses of Chiari Malformation came a lot of fear, tears, and questions. These questions went unanswered until I started researching the disease on my own. Knowing a little bit more about this disease, I started documenting what was going on with my son and went to his doctors with a little more knowledge and a lot of the "right" questions.

The next year Isaiah went from leg pain, occasional headaches to more frequent headaches and having what he calls "stars" in his vision to passing out in the middle of the street. This landed him in the hospital. I was told— it happened because of the Chiari, BUT not severe enough to do anything yet. Just watch him. Frustrating? That word I would not use just yet.

Over the next couple of years, Isaiah had a few more MRI's and I kept being told not severe enough to really treat, just keep an eye on him.

In 2003, things changed dramatically for Isaiah. He started having episodes where he would be trying to talk and it was as if he was struggling to finish what he was trying to say, his brain was not working right. In addition, this started to interfere with his schoolwork. Nevertheless, this still was not enough for his doctors. Then he started having intermittent blind spells—spells where he would go totally blind. He never knew when this would happen, it just happened. Now I have a terrified little boy on my hands and I am trying to comfort him, reassure him that he was not going blind. While doing this I am also dealing with his school trying to get them to have safety precautions put into place and trying to get him seen by doctors. The first doctor he sees, after his pediatrician was an eye doctor. Nothing wrong that glasses could not fix. Isaiah was still having blind spells. A neurologist could not see him for a few more months. In the meantime, it was suggested maybe he was doing this for attention; struggling with school, having problems adjusting, having problems coping with what was going on with me. You see during this time my doctors diagnosed me with syringomyelgia and Chiari (1). Isaiah saw me go from being ok to using a walker to being in a wheelchair.

After about ten doctors, six nerve blocks, medication on top of medications my condition "mysteriously" stabilized (the syrinx in my back closed up). I am now walking on my own. I am a little better, still having problems but I deal with it, especially since I know what is wrong. (NOTE: syrinx size does not matter, will still cause problems. The doctors said mine was no bigger than a pencil)

Anyway, Isaiah and I went to see a counselor. His diagnoses? Something more is wrong. In the meantime, Isaiah is steadily getting worse. His blind spells are coming more frequently, his speech is really bad now, and he is struggling big time. Now I am frustrated and mad.

I remember hitting my knees and screaming "No! No more! God if you are real show me what to do, guide me to where I need to go!" I had had enough. Between dealing with my own pain and doctors, I could not allow nor watch these doctors do this to my precious son. Therefore, I cried out to a higher power, one I have not called on for some time. When I got up off my knees, I knew what I needed to do. Some how fight, with every thing I had and I knew he was going to be right there!

A month later, my family and I sold majority of our possessions, packed up what we did not sell and moved to North Carolina. That was in February of 2004. In May of the same year Isaiah had another MRI and we were told his condition had worsen, the doctor recommended surgery. His surgery date was set for June 4, 2004. I cried all the way home and all night.

June 4th 2004- surgery day

I remember the surgeon telling me the procedure would only take 2 hours. Well, 2 hours came and went, my precious son was still in the OR. Praying and trying not to be upset, I sat and waited. Finally, the surgeon came out and talked to me. I remember him telling me "we had some problems, but Isaiah is fine and should be in recovery soon, you'll be able to see him then."

When I first saw my precious baby, I cried. Stroking his face I thanked God for bringing him through, thinking now he will be ok, it is all over. Wrong! Isaiah healed quickly and before too long he was back playing, playing basketball (which he loves), and being a little boy.

August school starts. He is ready and excited! A few months later, November, he starts having a lot of neck pain, ok that's understandable. Then December passes, then January. By mid-month, he is having problems swallowing and is choking on his food. Here we go again, with the tests and the doctors again. By March, Isaiah has to be pulled out of school, he is having swallowing and choking problems, headaches that are making him black out, and he is constantly missing school because of appointments. At first, the doctors thought there may be a tumor, the tests come back, and there is no tumor. So what's wrong? From what I understand, we are now dealing with the damage Chiari has done before his surgery. You see, the surgery stopped his Chiari, but now we have to deal with the damage Chiari had already caused.

Isaiah has severe migraines that affect him in several different ways: slur his speech dramactically, cause an immediate black out (no warning) or he will have severe pain. He also has acid reflux disease, which causes his swallowing and choking problems, he has extremely bad eyesight in both eyes, and he has chronic functional constipation disorder. (which is what we dealt with all this past week, almost put him in the hospital) from what his doctors tell me this is all part of Chiari Malformation (learned something new this week!) Isaiah was diagnosed with this disorder 4 years ago, first time someone besides me made the connection.

Dealing with this disease is very frustrating whether as someone who has it, as a parent of a child who has it or as a friend to someone who has it.

As a parent it is frustrating because you have to come to terms with the fact your child is sick, even though they may not look like it at times. (I deal with this all the time from spouse, relatives, neighbors etc.) Then you have to help your child find new dreams to have especially when they realize the ones they had they will not be able to go after. (Isaiah wanted to be a wrestler) You have to be strong and firm to get them to take the necessary medications, go to the umpteen tests they need or the doctor after doctor appointments required All the while being sensitive enough to know when they are in pain, because a lot of time they will not tell you until it is too late. Furthermore, you have to be their voice, especially when it comes to school. I know with Isaiah and school, if I did not stand firm and forceful, with out being mean, they would have him sitting in a classroom but not participating in any activities. I am constantly repeating, "Let him be as normal as possible with certain special boundaries."

As a person that has this disease it can be very frustrating at times. I personally have a lot of severe nerve damage to certain areas, like my hands, legs and other areas. I have good days and bad days. The most frustrating part of dealing with this disease is trying to get someone who is not dealing with it to understand. Meanwhile, trying not to come across as if you know more about this disease than the doctors do. So what are you left with? You have to find your middle ground, your comfort zone. I have learned to rely on a Higher Power, how to speak up loudly, and when to keep my mouth shut.

In closing I would like to say—we have to remember WE are not alone! We have each other. It is up to us to help educate others and make awareness of this disease known! HOW? By talking to others constantly and not giving up! By banding together, we can conquer this disease called Chiari.

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