Perspectives | 2.04

No, She's Not Fine!...By Tammy Wolfe

NO, SHE IS NOT "FINE"!! Those were the words I was screaming inside my head every time the words "she is fine... there is nothing wrong with her.... she looks like a normal healthy child" were uttered. My beautiful baby daughter was suffering and no one would listen to me. My daughter had extreme pains in her legs for years, but all the doctors kept telling me that the pains were nothing more than growing pains and she would grow out of it. Growing pains? Are you kidding me? Are we still living in the dark ages? She appeared normal to everyone else, but I knew deep down there had to be something terribly wrong with her. She cried and cried and at times could not walk. She would literally drag herself across the floor. Some days there were no symptoms and other days it was all I could do to console her. Her brother and sister felt she was crying to get attention and wanted her to "shut up". Tension was high in the household. There were many sleepless nights. My husband and I had concerns, but we felt our concerns were ignored as the doctors continually said there was nothing wrong with her.

My daughter had pneumonia a couple of times and was taken to the emergency room on each occurrence. During one of these visits it was discovered by a radiologist that her spine was curved and he suggested that we follow up with an orthopedic. An appointment was made and several months later she was seen. The orthopedic confirmed that she had scoliosis, but he was concerned that she had further complications going on in her body and we were referred to a neurosurgeon. My husband and I were terrified for our daughter, but relieved at the same time that her suffering would finally end. After MRI's and several tests, it was determined that my daughter had Chiari I Malformation, Syringomyelia and Scoliosis. We were just getting used to the fact that she had scoliosis, let alone these other two conditions which we couldn't even pronounce. The neurosurgeon recommended decompression surgery and the ball started rolling from there. Our friends, family and co-workers did not understand why she had to have this surgery because she looked "fine". There was that word again. It was hard to explain to them the definition of this condition as we had no idea of what it was either. Even after having it explained to us, we could not grasp the severity of this condition. On July 1, 1999, our 5 year old daughter underwent a five and half hour surgery. My husband and I, our two other children and my parents were on pins and needles. My husband who is a big, strong man broke down for the first time and did not want to let her go into the operating room. They had to literally pry her from his hands. When they finally said we could see her, I was not expecting her to look the way she did. It took all I had to not pick her up and run with her. What did you people do to our baby? My heart broke. She looked so tiny and pale and there was nothing we could do to help her. After five excruciating days in the hospital, we were allowed to take her home.

We thought she would heal and everything would be great. To our dismay, her leg/arm pains returned and her scoliosis got worse. She was braced for several years, but it did not hold the curves. During all of this, she missed a lot of school. Teachers were not sympathetic and my husband and I were even brought into the school's office for truancy. Our explanations were not good enough. We had to actually bring papers from the doctor that explained our daughter's condition. We even had one principal tell us "I have kids here with real problems and your daughter is not one of them". It took all I had to not slap her right across the face. Instead, we just walked out of her office. The ignorance of people is astonishing. The mentality is - if we can't see it, then apparently there is nothing wrong.... In addition, the medical society should make this condition and all the chronic pain that goes along with it more widely known to the public. To this day, our daughter still complains of leg/arm pains. She doesn't have normal reflexes/touch and the doctors believe that is due to the irreversible nerve damage caused by the Chiari I and Syringomyelia.

We were recently told that she will have to undergo the surgery where they place the metal rods in her spine. Our hearts sank once again when we had to sit her down and explain to her that she would have to undergo another surgery. She cried and cried, but my daughter is a very strong little girl. She is so worried about the scars. Some children already make fun of her scar down her neck when she wears a ponytail. How are they going to act when they see the scar down her back? Would she be able to ride a horse, would she be able to run, dance and be a "normal" child? Will the pains ever go away? Only time will tell...... but until then she lives her life to the fullest and deals with pain everyday. Something that I don't believe most adults would be able to handle. However, this little girl shows the world she is fearless time and time again.

My advice to anyone out there with a child who is experiencing similar problems is..... you know your child better than anyone else. Keep pushing the doctors until you get answers that you are satisfied with and don't let anyone tell you that you are crazy and your child is fine when you know otherwise. Research and arm yourself with knowledge concerning this topic, so that you can explain in laymen terms what Chiari I Malformation, Syringomyelia and Scoliosis is all about to people who just don't get it.

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