

There Is Nothing Wrong With Your Son

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 name is Melissa Jourdain, I am the mother of a young son with Chiari and have a tale like many others...."Nothing is wrong with your son, Mrs. Jourdain." If I had a dollar for every time I have heard that from someone who claimed to be an expert I could have bought Wyatt the medical care he deserved from day one. Instead, I played the system or was played by the system for nearly a year.

"Nothing is wrong with your son, Mrs. Jourdain."

Wyatt started to experience "headaches" when he was 2 1/2 years old. I hate to even use that term, because the word simply doesn't describe the terrible, indefinable pain he was in after doing simple things like running with friends, going to a birthday party, or driving home in our car. These activities, however normal, seemed to bring on excruciating headaches and lead to unbearable moments holding him in my arms, begging doctors to tell me what was wrong. The irony is, I have a Masters in Behavioral Neuroscience and have spent my career working with people with neurological disorders. I have conducted research on the brain for years and even teach psychology and biopsych courses at the collegiate level, yet I couldn't get a single correct diagnosis despite endless requests for imaging and more sophisticated diagnostic tools that could tell me something other than my child had a "sinus problem". Are you kidding me, "How could that be the culprit behind these headaches" I would ask? "How does sinus trouble explain stomach aches, cramps in his legs, tingles in his fingers, trouble sleeping, breathing, and seeing?" I was floored when our pediatrician told me that Wyatt got headaches, "because he goes to child care." Well if that isn't judgment of a working mother, I am not sure what is. At that moment I knew that my work and training to help the families of other people with brain injury, was really all in preparation for what would be in store for Wyatt and our family. Advocacy would take on a whole new meaning as we began to get help and answers for our son; as his symptoms grew worse by the week.

Wyatt had 24 doctor visits, several trips to the emergency room, rounds and rounds of Antibiotics, a CT scan, and one unnecessary surgery before we left this revolving door of medical care and took Wyatt out of the area to get an MRI. Within days of his scan he was diagnosed with a Chiari 1 Malformation with a Syrinx at C5. This was bitter sweet, finally an answer, but "What in the world is a Chiari" we asked ourselves? In all my years studying the brain I could not recall the term and relied on the Neurologist to explain. Within minutes of the diagnosis, we were already talking about the prognosis, which based on the scan meant Wyatt's surgery was not optional. "The decompression surgery was necessary to stop the progression of neurodevelopmental damage and paralysis," the doctor said and in that moment my heart stopped. I realize now after learning so much about Chiari, that many people struggle with the decision about whether or not to have the surgery. I can appreciate the gravity of that decision, but in hearing that Wyatt's case was not optional, it felt like I had been punched in the stomach. They were essentially telling me, there was no other choice, except to select a surgeon.

The idea of trying to choose the person that might...God and skill willing...be able to save my son was horrifying. "What if I choose wrong?" The thought haunted me. I suppose this is where all of our prayers paid off, because by a remarkable turn of events we found the genius, compassion, and patience of an outstanding pediatric neurosurgeon in California. Wyatt's surgeon was painstakingly thoughtful about every detail from making a perfect, linear incision, to choosing the correct Dura patch, and then to salvaging Wyatt's 2nd and 3rd vertebrae which had been in question about whether they could be saved and still ensure enough relief following the decompression. A standard Chiari decompression surgery takes about two hours; Wyatt's lasted for six hours due to the severity of his condition.

Wyatt is now preparing for his first post-op MRI later this month. It has been five months since his surgery on Sept. 15, 2006. I remember that day with the same intensity and exactness of detail as the day he was born. The sights, smells, and feeling can hit me at any time and I will relive that moment...particularly when they took Wyatt from my arms to prep him for surgery. Were it not for my husband's broad chest to sink my face into, I might simply have fallen to the floor. I have told many people that my heart only started beating again, when the surgeon came out to give us the news that "Everything went well, and Wyatt is one brave little boy." This of course we knew, of all the things we did not know, we were certain our son was remarkable, strong, brave, and resilient.

If there is a message in our story it is to be as resilient and brave as our children. Follow your instinct, in fact, let your instinct move you to collecting information and "gathering data"; we documented every symptom, behavior, abnormality, and quirk exhibited during Wyatt's year long battle. By the time we got to the neurosurgeon, I was numb, but he didn't hesitate to see the value in this "first time mom's" observations and excel spreadsheets, and he immediately made them a part of Wyatt's medical chart and referred to them when asking me specific questions.

I think about the man that Wyatt will become and imagine that he will never see an obstacle as insurmountable after having gone through brain surgery as a child. I also think about how to create a narrative for Wyatt that doesn't make him feel like he has a limitation, yet helps him to understand his Chiari and what it means for setting limits to his behavior. I can imagine what these conversations will sound like when he is 15...God help us! But in the same breath, I am thrilled to know that he will reach 15 and without a stubborn family, the hand of God, support of friends, colleagues, strangers, and one amazing neurosurgeon, this may not have been the case.

-- Melissa

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

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