3,000 Miles To Success For A Young Boy

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.*

Our son, Jack, is three years old. Of course, as proud parents, he is in our humble opinion the most beautiful, intelligent, and wonderful gift from God any parent could ever want. He walked at nine months, talked at 12, and was running shortly thereafter. At 18 months, we experienced what we thought was a tragedy but turned out to be a blessing. While playing in our kitchen, Jack fell and hit his head on the fireplace. We immediately rushed him to the hospital, where they performed a CT scan. We were relieved to learn that Jack had not fractured his skull, but we were referred to a plastic surgeon. Needless to say, the "blast" (as the plastic surgeon called it) on Jack's forehead was nasty, and it required several stitches to close.

But the story was not even close to over. A few days after the stitches were placed, Jack developed a very high fever. His pediatrician immediately sent us to Children's Hospital of Philadelphia (a 30 mile trip from our home) to rule out bacterial meningitis from the fall. Jack underwent a second CT scan, a lumbar puncture (better known as a "spinal tap"), and a host of other tests. Fortunately, he did not have meningitis but instead just a bad virus that coincidentally reared its head at a very bad time. More importantly, however, the radiologist who reviewed the CT scan recommended a follow-up MRI to rule out a possible Chiari -- and our lives were changed at that moment.

Fortunately, we live so close to several top hospitals in Philadelphia that finding a world class neurosurgeon was easy. Jack was seen at Children's Hospital of Philadelphia, and after an MRI, it was confirmed that he had an 8mm Chiari malformation without syrinx. We later learned that his CSF flow was restricted in the hindbrain area. We were devastated. However, Jack was, as best we could tell, asymptomatic at the time. As a result, Jack's neurosurgeon recommended that we monitor his condition.

From that moment on, my wife and I read just about every article we could find on Chiari malformations. We cried, debated, argued, and prayed. And I called just about every major hospital or practice group that specialized in pediatric Chiari who would listen. I called Johns Hopkins, the Cleveland Clinic, Children's Hospital of Philadelphia, our new pediatrician (who was familiar with Chiari), Chiari patients, and a few others, and I asked every question that came to mind. I spared no one the full brunt of my interrogation, and every single doctor, nurse, patient, friend and stranger responded with understanding and compassion. It was an amazing experience.

Then, just when I thought I had exhausted all my research and satisfied myself (and my obsessive compulsive disorder) that I knew what to do, I happened to find the Conquer Chiari website and read about a world class pediatric neurosurgeon at UCLA by the name of Dr. Jorge Lazareff. He appeared to be an expert in Chiari, as well as a wide variety of other complicated neurological disorders, and had pioneered a new procedure to minimize the trauma of decompression surgery in children. Within seconds I was on the phone with Dr. Lazareff's assistant and she very nicely told me to send Dr. Lazareff an e-mail and he would respond. So I sent the e-mail, and, sure enough, I received an almost immediate response. Dr. Lazareff responded to my questions and welcomed the opportunity to discuss with me Jack's condition. What would happen next is almost impossible to believe.

Shortly after that initial e-mail, I was on the phone with Dr. Lazareff. He called me on my cell phone to discuss Jack's case. We spoke for more than a few minutes. He offered an unending stream of advice, answered and re-answered all of my questions, and offered to review all of Jack's studies so he could provide a second opinion. For the next several months, Dr. Lazareff served as our "consulting neurosurgeon", sounding board, friend, confidant, and guardian angel, all from 3000 miles away and having never met us. He was a blessing beyond words, and we needed a few blessings.

A few months later, in the summer of 2005, Jack fell very strangely a few times. He had what are sometimes called "drop attacks", where he toppled over for no reason. As a very articulate two-and-a-half year old, when my wife asked Jack what had happened, he stated very simply that he had become "dizzy" and fell. (he knew what dizzy meant only from regular games of ring-around-the rosy with his mother). Our concern raged very quickly, and I think we knew that he was becoming symptomatic. The CSF flow study followed, and it confirmed that Jack's flow was restricted. Both doctors recommended surgery in the near future. Devastated is not sufficient to describe our feelings.

But Dr. Lazareff never wavered. He told us not to worry, that Jack was not sick and did not have a disease. He made clear that he had an anatomical condition that could be corrected with surgery. He answered every one of my additional e-mails and called us at home at times convenient to us,

Finally, we had a decision to make, and it was not an easy one. We had to choose who would perform Jack's Chiari decompression from among two world renowned neurosurgeons, one of whom was 3000 miles away. We had direct access to Jack's local physician, but we had only spoken to Lazareff on the phone, albeit too many times to remember. So, we scheduled one final conference call with Dr. Lazareff, which he gladly accepted. Prior to the call, to help focus the conversation, I e-mailed to Dr. Lazareff approximately 40 questions that I wanted to address during the call. They were intended to be talking points, nothing more. Instead, Dr. Lazareff took it upon himself to answer in writing every question I asked and sent the responses back prior to the call. We were completely amazed. He answered questions about his interests, his experience, his education, the procedure, Jack's prognosis, complications, and travel to and from California with a child who would have brain surgery.

Shortly after that call, we made our decision -- we were going to UCLA, and Dr. Lazareff would perform the procedure. He would perform the Chiari decompression at our convenience (he told us to pick a day). He would open the dura, use Jack's own tissue for the dural graft, manipulate the tonsils as necessary, and replace the small piece of skull with dissolvable screws. He would not do a laminectomy. Dr. Lazareff explained that he did not believe that the laminectomy was necessary to correct the condition, and that there was no additional risk to not performing it. In fact, he made clear that he does not perform it, and that is the only way he would do the surgery. He provided clear clinical data, which we knew was a departure from most decompression surgeries, but we were satisfied. When it came to the laminectiomy issue, Dr. Lazareff was adamant in his resolve.

In October 2005, we flew to California to have Jack's surgery. The trip was all about Jack. We made it a vacation, and Dr. Lazareff and his assistant helped us plan some of the activities. We went to Universal, Disney Land, the Santa Monica Pier, great restaurants, and stayed at the Beverly Hills Plaza. The hotel was only a short couple of miles from the medical center. They knew Jack would be having brain surgery and that we would be there for a week after the procedure. They treated us -- and more specifically Jack -- like royalty. Whatever we needed, they provided, and they asked about Jack every day. Even the door men wanted daily updates on his condition.

As for the surgery, it was long (nearly six hours from the moment we handed Jack over to the doctors until we saw him again). But the staff at UCLA was remarkable. Several doctors met with us that morning, and Dr. Lazareff came to see us right before he went in to surgery. Jack was very gently sedated, and then one of the doctors carried Jack to the surgical wing. We followed directly behind, gave our kisses, and then waited for what seemed like an eternity. The next thing I remember is the smiling face of Dr. Lazareff when he came to meet us after the procedure to tell us everything had gone exactly as planned and that Jack would be fine.

We saw Jack in recovery a few minutes later. Although he was sore -- this is brain surgery -- he never needed any heavy meds after the surgery. Prescription Tylenol suppositories every four hours were all he needed. The next morning he was sitting up, watching TV, reading books, and eating and drinking. To us it was a miracle. To Dr. Lazareff it was nothing. Jack spent the next couple of days in the hospital regaining his strength and enjoying the attention of numerous nurses who were always there. Jack entertained them every chance he had. On the third day after the procedure, Jack got up and took a walk. From that point on, he was ready to go. The next day he was released with virtually no restrictions. We stayed in LA for another few days to make sure he was fine. Seven days after the surgery we saw Dr. Lazareff for the final check-up. Jack was fine and released to go home. We took a picture of Jack with Dr. Lazareff hugging him that has a very prominent place in our home. We thanked him profusely, and he seemed embarrassed by it all. He is as humble as he is caring, passionate and gifted.

Since our return home, I have been in contact with Dr. Lazareff almost weekly. We have talked on the phone and corresponded by e-mail, and he has never failed to respond. As Jack healed, we had numerous questions about his aches and pains. Dr. Lazareff was always calming and seemed to have the answer. He even sent me an e-mail shortly before he left for China for a week of neurosurgery there and told me if I had any questions to write and that he would respond from Asia.

Last week, Jack had his follow-up MRI. The MRI confirmed that the surgery was successful and that Jack is fine. His tonsils are no longer crowded, no syrinx is present, and his CSF flow has been restored. Dr. Lazareff also confirmed that we should not expect the condition to return. He explained that although many patients do have recurring symptoms after surgery, Jack's was caught early and the procedure as Dr. Lazareff performs it resolves the condition for good. Jack was released with no restrictions.

In the end, I'm not sure where this journey will lead us, but if Dr. Lazareff is correct, we have put Chiari malformations behind us. In the meantime, we pray everyday that Dr. Lazareff can do for others what he has done for our son. God puts people in your path for a reason, and as I passed through the Conquer Chiari web site, I found Dr. Lazareff. For that, we are very grateful.

We also have a few suggestions to all those dealing with Chiari:

1. Talk to every expert you can and objectively analyze their opinions.
2. Don't ever take no for an answer. We knocked on a lot of doors, and most people answered.
3. Get multiple opinions before surgery.
4. Find the best doctor who makes you feel the best about your individual condition. Not all Chiari patients are alike.
5. With a child, don't delay any aspect of the diagnosis or treatment. We intervened early, and as a result, Jack's cerebellar tissue was normal because it had not yet been damaged by the pressure associated with Chiari.
6. With a child, do everything you can to focus on aspects other than the surgery. Jack knows he had brain surgery, but all he remembers is Disney Land, Dr. Lazareff, and his "home" in California.
7. Do the research and challenge the doctors. Jack had three separate MRIs prior to Dr. Lazareff (head, neck and CSF flow) when he could have had one or two.
8. Be relentless. This condition can be resolved in many cases, and it takes a truly gifted neurosurgeon to make that happen.
9. Enlist the help of your family physician. They are great sounding boards and can help facilitate getting test results faster in many cases.
10. Never give up or lose faith. I prayed a lot, but my wife never lost faith. I learned along the way that there's a real difference.

With all our hope,

Rob and Jennifer Carmignani

*** Do you have a Good News Story to share? Let us know at director@conquerchiari.org ***