

In August 2005 through a routine sports physical I found out that my then 4 year old daughter Lorena had scoliosis so her pediatrician referred us to an orthopedist. My initial thoughts were where did this come from and why did they not see anything at her well check 9 months prior after all it was the same pediatrician that had been seeing her since birth.

Lorena was seen by a pediatric orthopedic two weeks later and an initial x-ray showed a 26° thoracic curve and she was sent to get an MRI. In September at her follow up appointment we were told that her MRI was normal and her x-rays showed a curve of 22° so the treatment at this point was watch and wait. We left the office that day full of joy and hope that all would be okay after all. In December 2 weeks before Christmas we found out that Lorena had grown 3 inches since her initial appointment in August and that her curve had progressed quickly to 42°. My husband and I were both completely devastated the Dr said that at this point she would have to wear a brace 23/7 and ultimately at some point hopefully a minimum of 8 years down the line we would have to consider fusion he also mentioned something about experimental east coast another doctor ~ I honestly don't remember after the word experimental I quit listening and my thoughts were on the brace she was going to have to wear. Over the next day or so I took her to for her brace fitting and I resolved that the brace would be fine, it was no big deal, after all Butch the brace guy said she did well during her fitting and most kiddos who did well being fitted did well wearing the brace and complying with using it as it should be. I put the whole fusion thing behind figuring I would deal with that when I needed to.

In January we picked up the brace ~ it was immediately horrible for her and for me but I had to be strong and not let her see that it bothered me. I put on a big smile and told her see its no big deal; you can't even see it under your clothes. Erik our 17 yr old had gone with us that day and he too put on a brave face for his little sister but we both saw how scared she was and we both avoided eye contact with her for fear that she would see our fear. We left and decided to go out for dinner and we took her to her favorite place Applebee's and I told her she could skip real food and have her favorite dessert. She opted for cheese sticks and dessert, it was the worst meal ever after about 3 bites she couldn't eat anymore her brace was so tight her tummy was instantly full and she just sat there crying and didn't even touch her dessert. We all went home with empty stomachs and hearts full of sadness. The first few days were a challenge dealing with the brace, undershirts, rashes, witch hazel, baby powder, etc. but we got along and before we knew it two weeks had gone by and Lorena had her first set of in-brace x-rays the brace was doing it's job and her curves were in the mid 20° range I don't remember exactly but the Dr thought it could be better so he adjusted the strap and took another set of x-rays and the curve was down to about 18°. But I was eager to hear more about this experimental thing he had mentioned to us before. He explained to me all about the vertebral stapling procedure and gave me the info on the hospital. I looked up everything I could find on the internet, I filled out and faxed in the application and made my first call to Janet Cerrone she called me back the next morning and from everything I told her she said it sounded like Lorena was the perfect candidate for the vertebral stapling procedure. She asked about our application and said she would try to push it through a bit quicker than the normal 30 days and low and behold that same afternoon I received a phone call and her initial appointment was scheduled for February 16<sup>th</sup> @ 8:00 AM with Dr. D'Andrea.

Dr. D'Andrea was wonderful, she looked at all of her x-rays, examined her, looked at her MRI and pointed out another curve we didn't even know existed. She very thoroughly explained the procedure and what all was involved. She was quick to say she could not make any guarantees, she felt Lorena was a good candidate but would not agree to staple the upper curve until she had a CT scan with contrast done to see if she could safely staple the upper curve. She also agreed with our local orthopedist that without this procedure she was 99.9% positive that she would need fusion later on.

We flew back home to Texas with more questions and more concerns all of which were addressed by Dr. D'Andrea and Toni Williams. Once the CT scan results came back Dr. D'Andrea said she was comfortable stapling both curves it was our decision as to weather or not we wanted to move forward. We discussed it and ultimately let Lorena have a say in our decision. We made sure she was fully aware of what was going to happen to her, what they were going to do and asked her opinion. She asked if after surgery she was going to

have to wear her brace and we honestly told her we did not know it was possible she did and it was possible she didn't. Then she said well if it is possible she didn't have to wear it she wanted surgery because otherwise she knew for sure she had to wear the brace.

We were put on a wait list and after about 2 months we were given a date of June 26<sup>th</sup>. From the time we walked into the hospital until the time we walked out Lorena could not have had better care. Ultimately Dr. D'Andrea stapled T2-T6 and T6-T12. Everyone tries so hard to insure that these children are comfortable and at ease. The nurses go out of their way to keep you abreast of what is going on during the surgery and afterwards their only concern is that the child is comfortable and free of pain.

Lorena was discharged on Thursday June 29<sup>th</sup> and to this day if you ask her what the worst part of surgery is she will tell you taking off the tape is the worst part. She looks forward to her trips to Shriners. We have since had the pleasure of meeting Dr. Betz who is also nothing short of amazing. Lorena's 6 month post was with Dr. Betz and although he'd never actually seen or met Lorena; he knew exactly who she was from the films. Dr. Betz and Dr. D'Andrea have both agreed to work with our local orthopedist so we don't have to travel to Philadelphia every 3 months we are alternating our Dr visits between here and there so we go to Philly only once a year.

During our entire brace wearing ordeal I was so focused on making sure Lorena wore her brace properly and keeping her active enough that she didn't think about her brace that I or we for that matter never noticed how unhappy she was. Our once very popular and outgoing daughter was now shy and withdrawn and she stopped laughing the day she got her brace. We realized this only when we heard her laugh again; it was the best sound we had ever heard her laughter once again filled our home.

Shriners has not only helped Lorena by giving her almost two brace free years Shriners gave us back our daughters confidence and best of all our daughters laughter; something we missed just didn't notice it right away. All of this and to top it off she is doing great her last x-rays measured a curve of 22°.

We are eternally grateful to Shriners Philadelphia for everything.