

## LEXI'S CASE

Our daughter Lexi was officially diagnosed with Infantile Idiopathic Scoliosis at one year old. Her curve was first detected at 4 months old, but dismissed as her position while the x-ray was being taken. When she was finally diagnosed we were faced with the decision of how to move forward with treatment. We initially tried serial plaster casting, but in January of 2006 we decided to try treatment with a brace and began to see Dr. Gomez.



When we initially consulted with Dr. Gomez, Lexi had a thoracic curve of 38 degrees and a secondary lumbar curve approximately 23 degrees. At this time she was 2 years and 3 months old. Dr. Gomez decided to measure Lexi for a TLSO brace to treat her curves. I will admit in the beginning I was very apprehensive about a brace, as I heard from other parents who had tried bracing either did not or currently were not getting good results. Lexi was fitted with her brace 2 weeks later and so our journey began with treatment wearing a brace. What I will share with you is from a mother's standpoint. I can relate to the confusion of trying to understand and the difficulty in trying to make decisions that will ultimately affect your child's well being. Being a parent to a child without medical issues is tough enough, but add in something like scoliosis which is not always easy to understand, and then your job just became a lot more difficult.



Right now Lexi has obtained impressive (to me at least) reduction in her curve. Like I said above when we began with the brace, her curves measured 38 degrees and 23 degrees. As of May 2006 her thoracic curve was around 12 degrees and her lumbar curve was zero degrees. As well as reduction in her curve I have noticed phenomenal changes in her balance and her symmetry. Before the first brace, Lexi leaned toward the clumsy side; she would fall down quite often and seemed to trip over her own feet. It was not until the brace began to balance her out that I realized it wasn't her age or clumsiness, it was her body not being balanced and aligned properly! Lexi stands taller, walks better and looks so much better than I could have imagined. It was not until we met with Dr. Gomez and began to learn about his approach that I fully understood the importance of balance and symmetry in my daughter. To get her spine more corrected was one thing, but she had to gain stability and balance on all planes for any of this to really work. I personally think this is a huge misconception amongst parents out there whose children have scoliosis. Like so many of them, I was told several times that the ultimate goal is to get that spine to a zero degree measurement. I became obsessed with this and now I have learned through watching Lexi that even though she still has some curvature, she looks straight and she is balanced. I have come to realize as well that Lexi may never have a completely straight spine, but that she may function more stably with a slight curve. As a parent, this was a hard piece of information to swallow. I had become trained to believe that a straight spine was the ultimate goal and anything less was unacceptable.



As a mother, I also understand it is hard to deal with your child spending an unknown amount of time in an orthotic device. This has to be one of the more difficult processes to get through, and I am still working on this everyday. Lexi began this at an early age, and she is used to her brace. We make a very big deal about her "special brace" and always pick some of the more outrageous designs and colors to make it fun for her. However, we are committed to treating her so that surgical intervention is hopefully never needed. I cannot imagine putting her into an operating room for fusion surgery or to have metal rods placed in her to hold her spine straight. I would much rather her wear this brace day in and day out to never have to see that happen. I hope when she is old enough to understand, she realizes why we are doing this, not to her, but for her! As a family, we always stay positive for Lexi when talking about her brace. She learns from this that it is a

positive thing and not something to learn to dislike or not want to wear. Building up self-esteem in these children with devices is the most important tasks we have as parents. If they pick up from us that the brace is a negative thing, they will begin to think there might be something wrong with them or have self-doubts about themselves and their image. As a parent, you have to keep this in a positive light. I know a day will come when a child makes fun of Lexi. I want her to be strong enough to know that she is perfect and there is nothing wrong with her in anyway. The psychological part of getting yourself through this and your child through this I feel is the toughest part of it all. Remember, the long-term goal of watching your child come out of a brace one day versus the possibility of fusion surgery is definitely worth the time spent in a brace.

One other point I want to stress is this. I feel that Dr. Gomez's approach to making these braces is exceptional. He looks beyond just the curve, he looks at the patient as a whole. The symmetry, the balance...the whole body is involved. His braces are made from a biomechanical approach...the brace works with Lexi. She is not hindered in anyway from normal motions or movements. As far as it all goes as a whole, I do not understand the entire biomechanical system in these braces, but I do know from the results we are getting that it does work. Dr. Gomez puts a lot of time and effort and personal care into Lexi's case, as I am sure he does all of his cases. He also involves the parent's in the treatment. We are also a part of this team, and he makes sure we are educated in knowing what to look for, when the brace may not be fitting right, and if the pressure points are leaving too much of a red mark on the skin. As a parent I feel we are one of the most vital team members as we are with our children all of the time. We have to know what is going on as well, and Dr. Gomez makes sure we are aware of everything.

There are many wonderful things Lexi is doing as well in her brace. Wearing it does not stop her or slow her down in anyway. She climbs the jungle gym with it, although we watch her very closely while doing this in brace. She runs and plays just like every other child in her preschool class. She will begin ballet lessons soon to and of course will spend the class time out of her brace. This will be wonderful exercise for her back too. She is still a very normal and active toddler and we love watching her grow everyday and love the progress we are seeing from such a gentle, non-surgical treatment for her back.

*Newspaper Article*  
**Observer Reporter**

**Fighting for Lexi**

by **Luisa Hart** 6/29/2006

Ruled as the way Lexi was lying while the X-ray was being taken, Tracey and her husband came to forget about the curve. "We weren't concerned at the time," said Tracey. "We didn't know it was anything significant." Fast-forward to October 2004, 11-month-old Lexi was getting ready for a bath and her parents notice her rib cage is humped to the right on her back and her shoulders are not even. By January 2005, Lexi is diagnosed with Idiopathic Infantile Scoliosis. "We were given no treatment options, nor were we told it was anything to worry about," said Tracey. "We felt lost." Tracey immediately went online and tried to find as much information as possible about Idiopathic Infantile Scoliosis. What she found was a group called Infantile Scoliosis Outreach Program, or ISOP, started by a mother in Colorado whose daughter battled severe scoliosis.

According to the ISOP Web site, [www.infantilescoliosis.org/](http://www.infantilescoliosis.org/), Infantile Scoliosis is a lateral spine deviation that occurs during a child's first three years. Approximately 74 percent of cases resolve on their own. Of the 26 percent that don't, scoliosis not only causes physical distortion but can also put internal organs in jeopardy if the case is severe enough. Physicians use a Rib Vertebral Angle Degree, RVAD, to measure the amount of curvature and severity of the scoliosis. According to the Web site, [www.ahealthyme.com/topic/scoliosis](http://www.ahealthyme.com/topic/scoliosis), a normal spine, the rib-vertebra angle difference at any vertebra is zero.

"When Lexi was officially diagnosed in January 2005, her curvature was 22 degrees-they thought it would self-resolve. We were told to wait, and I knew we could not wait," said Tracey. "We had to get Lexi help." On the Web site, Tracey read about a treatment being done by two physicians with Shriners Children's Hospitals. One physician is located in Salt Lake City, Utah, and the other in Erie, Pa. Both are using a technique perfected by Dr. Min Mehta, of England. According to [www.infantilescoliosis.org/](http://www.infantilescoliosis.org/), under general anesthesia, the child is straightened as much as possible and then placed in a plaster cast.

This will hold the spine in its corrected position for two to three months and then another cast will be placed and continue until the child is straight. In August of 2005, Lexi and her family traveled to Erie, Pa., for her first cast to be placed. Her curvature was measured at 38 degrees. Once the cast was put on, it was corrected to 13 degrees. In November of the same year, Lexi received her second cast and was able to continue at 13 degrees. Upon returning to Houston, the family had to learn to live life with a cast. "While challenging at first, we adapted as did Lexi," said Tracey. "This was worth the struggle, as we knew if left untreated, one day she would end up in an operating room having to have metal rods fused to her spine to straighten it. We would not let this happen." But life may have gotten a little easier for Lexi, thanks to Miguel Gomez from Dynamic and Orthotics & Prosthetics in Houston.

"We have a wonderful orthotist who is making her braces and has a very innovative approach to doing this," said Tracey. She went on to add, "His own daughter suffered from scoliosis and he knows the dangers if it is left untreated." Dr. Gomez obtained his medical degree in Colombia and makes prosthetics and orthotic devices in Houston. In January 2006, Lexi was put in a brace she wears 23 hours a day.

"Her curvature is now at 12 degrees and holding," said Tracey. It's unknown how long Lexi will have to wear the brace, but that hasn't stopped her, or her parents, from laughing and seeing the

world through the hopeful eyes of a toddler. "Lexi loves a lot of things. Her main love is, honestly, shopping for shoes. She loves to dance like a ballerina and loves to spend hours on her art easel with her colors," said Tracey. "She loves to swim, which is great therapy for her back and helps strengthen the muscles in her back. She also loves the playgrounds and her brace does not keep her from playing like any other child." "The most important thing is this," continued Tracey.

"If your child is diagnosed with infantile scoliosis, early treatment is the key. With waiting comes the chance for the scoliosis to become more destructive. If you suspect your child may have a curvature, seek the opinion of a pediatric orthopedist, one who takes an interest or specializes in scoliosis. We were told to wait by ours and I did not agree. We fought about her treatment. Interesting fact-According to the Web site, [www.ahealthyme.com/topic/scoliosis](http://www.ahealthyme.com/topic/scoliosis), girls are more likely to develop scoliosis than boys. Children with Infantile Scoliosis can fall into two categories, Congenital and Idiopathic. Congenital means there is a structural cause for the scoliosis, like vertebrae abnormalities. Idiopathic means there is no known cause for the curvature. Web sites: [www.infantilescoliosis.org](http://www.infantilescoliosis.org) [www.scoliosis.org](http://www.scoliosis.org) Dynamic Orthotics & Prosthetics in Houston. [www.dynamicoandp.com](http://www.dynamicoandp.com) Warning Signs According to the Web site, [www.ahealthyme.com/topic/scoliosis](http://www.ahealthyme.com/topic/scoliosis), here are some things you should be looking out for:

- \*A child's shoulders may be uneven
- \* one or both shoulder blades may stick out \* the waist may be lopsided
- \* the hips may seem unusually high, or
- \* The child may lean to one side. If you notice asymmetry, it's a good idea to have the doctor check it out.

### *Picture Gallery*

