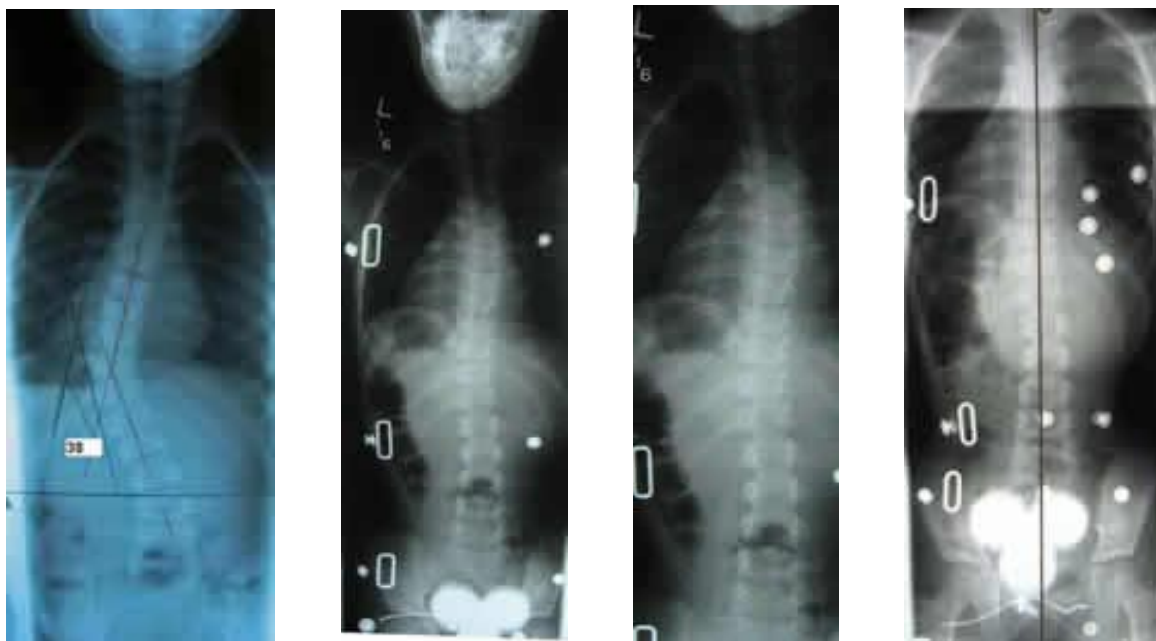


## SARAH'S CASE

Sarah was diagnosed with scoliosis at 5 ½ years old. At her 5-year-old check-up in April 2003, she had a routine screening for scoliosis but no curve was detected. Six months later, after noticing during the summer, particularly in her bathing suit, that Sarah just did not look straight, we decided to have her checked again. An X-ray showed that she had a 37-degree left-facing curve from her lower thoracic (T-7) to her upper lumbar (L1) vertebrae.

Medical issues for Sarah were not new to us. At 6 months of age, Sarah had surgery to remove a tumor from her abdomen, after which she had a lot of feeding/vomiting issues for several years, being hospitalized for dehydration on several occasions.



At the time of the scoliosis diagnosis, we were faced with a daunting future for her. We were initially told that since she was so young, and had a lot of growing left to do, she would most likely end up with surgery to fuse her spine. We were told that orthotic braces to treat scoliosis would only stabilize the curve she already had in an attempt to prevent it from getting worse; they were not designed to correct the curve. However, we were also told at that time that there was no way of predicting how she would respond in a brace. Her curve had progressed rapidly (undetectable to 37-degrees in six months) and was classified as neither infantile-scoliosis nor adolescent scoliosis; and, while several theories were given, there really was no consensus as to the cause. Fortunately, an MRI ruled out more serious issues, although there was the possibility of a tethered spinal cord. We are currently using the somatosensory electrode potential (SSEP) results to monitor this, but feel confident at this point that she does not have a tethered cord.





We felt that we should try the most conservative approach possible first. Sarah's first Orthopedist recommended a traditional Boston Brace. After wearing it for several months, we decided to seek a second opinion. The new Orthopedist looked at Sarah's latest X-rays and discovered she had two curves; a right-facing T12-L4 curve as well as a left-facing T7-L1 curve. We could not understand what was going on.

We then consulted with Dr. Gomez, the Orthotist who would be making Sarah's new brace. Dr. Gomez explained the issue. The goal was to create a spine that was both straight and stable. The Boston Brace Sarah had been wearing was pushing on her original left-facing curve in order to straighten it. In order for the curve to straighten, Sarah's spine had created a compensatory right-facing curve. So, while Sarah was appearing to "look" straighter, her spine was just responding to a one-dimensional force. It was not creating any kind of stability.

Dr. Gomez's approach was quite different. Rather than just creating a force directly on the original curve, he looked at her entire spine in all three-dimensions. He explained that in order to create a straight spine that was actually stable, one had to apply the proper force in all three dimensions. The spine had to be straightened from the base upward. He explained that the issue was similar to the Leaning Tower of Pisa. You can make that tower as straight as possible, but it is still going to lean unless you look at it from all dimensions; the X, Y, and Z axes.

Sarah has been under Dr. Gomez's care since October of 2003. Since then she has had several different braces, all addressing different issues and applying different forces in different areas as she has grown and changed. Currently, both curves in her spine, as measured by X-ray are so negligible, the Orthopedist does not even assign a number to them. But, more importantly, clinically, she is also quite stable.



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Sarah has been extremely cooperative and positive about wearing her brace. We have never seen it in a negative light. Of course it helps that it comes in a wide range of "cool patterns". Currently she's into the "cheetah" style; having outgrown the "butterfly" phase. We have always viewed it as a ticket out of surgery, as a tool to avoid spinal fusion, as an amazing piece of engineering. We have been committed to wearing it as directed, 23 hours a day, because we understand that this is a small price to pay for enormous benefits later. Plus, the brace does not show underneath her clothes so no one even knows she's wearing it, unless she chooses to tell them.

However, we have come to realize through this experience that the brace is only as good as the design and the designer behind it. Dr. Gomez's expertise has really made the difference. He has a keen understanding of the physics, the various materials, and the specific medical issues that underlie the issue. He takes a large number of measurements and considers a variety of factors when designing each of Sarah's braces; taking into account which forces need to be placed in

which areas, and to what degree. It is this attention to the specific details of each individual case that truly impresses us. We do not just have a generic "scoliosis brace"; we have a brace designed for Sarah's specific needs at each particular time. On top of this, Dr. Gomez is one of the most humble and respectful doctors we have ever met. He takes the time to explain our specific issues, not only to us as parents, but to Sarah as well. His open and honest communication style really aids in our understanding, Sarah's positive attitude, and ultimately to our success in treatment.



If you have any questions about our experience or about the brace, please feel free to contact us.

## HOW OFTEN SARAH WEARS HER BRACE:

Sarah must wear her brace 23 hours per day. She may take it off for 1 hour. This hour should include showering time.

## EXCEPTIONS:

1. Swimming: Sarah does not wear the brace when swimming. Time does not count when Sarah is out of the brace and in the water swimming. If she swims, for example 5 hours in one day, she still gets her 1 hour of time out of the brace when she is no longer swimming
2. Exercise: Sarah can get an additional 1 hour out of her brace each day as long as she is exercising during this 1 hour period - particularly exercise that uses her back muscles; for example, horseback riding, gymnastics, running, etc.

## HOW TO PUT ON THE BRACE;

Sarah can fully assist in putting on her brace, except for the top strap which requires adult assistance to make sure it is exactly straight.

1. Her special T-shirt goes on underneath the brace. She puts this on herself. It goes on backwards (the low neck goes in the back).
2. The straps of the brace go in the front:
3. She can put it on by herself, with minimal assistance for opening up the brace to help her fit herself in it
4. She needs help to make sure then the T-shirt is pulled taut to remove as many wrinkles as possible
5. She needs help to make sure the underarm flaps are pulled up over the brace to protect her underarms from the plastic edges
6. Start by putting on the bottom straps first. She lays on her back with her knees bent. Make the straps straight and relatively tight. She can let you know what is tight enough



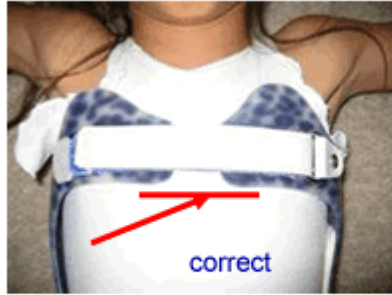
Bottom strap is done 1st



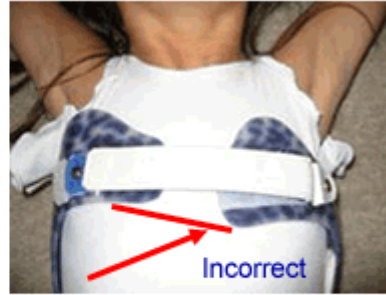
Middle strap is done 2nd

7. The top strap is slightly different. It absolutely needs to be straight before going through the metal loop. Align the plastic sections so that the bottoms are horizontal with each other and attach to the Velcro before inserting the strap into the metal ring.

### Here is the correct way



plastic is horizontally straight



plastic is not horizontally straight

Notice, the incorrect way shows the bottom plastic portion of the brace not horizontally even, although the actual strap is "straight".

### IMPORTANT POINTS TO REMEMBER:

1. **The brace cannot get wet:** If Sarah is to be involved in any kind of water or exposure to water activity while wearing the brace; she must take the brace off. No water-balloons, for example, while she is wearing the brace. Also the brace should not be exposed to sand - it would be impossible to clean making it very uncomfortable
2. **Please check her skin:** When taking the brace off and/or putting it on, please check her skin - particularly her chest area where the top strap of the brace sits - it often gets red. Do NOT put any lotion on these areas, simply loosen the strap for a few hours and see if it gets better. If it does not bother her, then do not worry about it. It's never been so seriously red that anything has had to be done about it so I do not anticipate any problems
3. **Tighten the brace in the morning:** When the brace is put on at night after a meal, all three straps may not go over as far to the left as if it is being put on in the morning before eating. That is OK as long as they are relatively tight. If the brace is put on at night and the straps are not too far over, please remember to tighten all three straps in the morning (after she's digested and slept) - we usually write a note to remind ourselves to check the tightness of the straps in the morning



Notice the straps go far to the left (Typical for the morning)



Here the straps do not go all the way to the left (Typical for after a meal)

4. **Activities Where She Can Fall from a High Place:** It is preferable that the brace be off during activities in which she can fall from a significantly high place (horseback riding, climbing high on ropes, etc.). She would be limited to 1-2 hours of those activities per day. For jungle-gym type activities where a fall would not be significantly high, she can wear her brace - just make sure that someone is spotting her. The issue is that there is not much room for her spine to move for shock absorption purposes if she falls.