

AHEAD OF THE CURVE

THE OFFICIAL NEWSLETTER OF SETTING SCOLIOSIS STRAIGHT

The Harms Study Group is a group of surgeons dedicated to the advancement of treatment for children and adolescents with spine deformity. Through comprehensive, multicenter prospective research studies questions regarding treatment approach and treatment techniques to achieve desired outcomes are studied.

THE HARMS STUDY GROUP FOUNDATION GETS A NEW NAME!



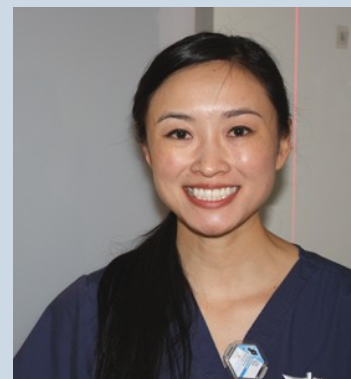
*Supporting Discoveries
in Spinal Deformities*

Welcome to our first newsletter of 2012! This New Year brings with it many changes for our foundation. First and foremost, the biggest change is our name change. In an effort to better communicate what kind of work we do to those who are unfamiliar with Harms Study Group, the Harms Study Group Foundation has been rebranded, and we are now Setting Scoliosis Straight! The Harms Study Group will still be identified within the foundation as: **Harms Study Group... 'Pioneering Research in Spinal Deformities'**. It was our goal to find a name that clearly reflects our mission. We hope

that this name will resonate with our patients, readers and others who are looking for the most up to date information on adolescent spinal deformities.

LONG TERM FOLLOW-UP WITH ONE OF SAN DIEGO'S GRATEFUL PATIENTS

My name is Lisa, and I am currently 26 years old. I was diagnosed with scoliosis when I was in middle school during a physical in P.E. I was unfamiliar with the condition, and it was all very frightening for me. Initially, I was referred to Dr. Peter Newton at Rady Children's Hospital and was fitted for a brace that I was supposed to wear twenty-three hours a day. I tried my best for a year, but it eventually became so uncomfortable, and I felt so self-conscious that I stopped wearing the brace to school. I had surgery in October of 2000, just one month into my freshman year of high school. The immediate days following surgery were a struggle. I was very dependent on my family and had to relearn simple tasks like walking and sitting up. Slowly but surely, I was able to move about freely with some limited physical activity. It was a journey.



Lisa on the 3D EOS X-ray machine

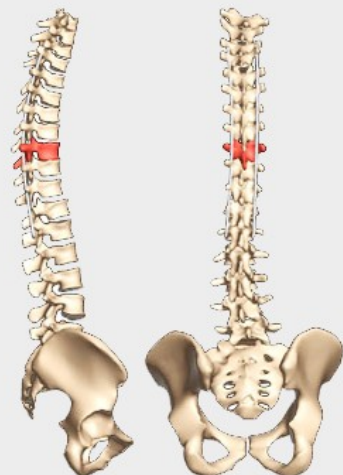
I am very grateful to have had such an awesome experience with the doctors and nurses at Rady Children's Hospital. Throughout the years they have continued to stay in contact with me and have really helped me become the confident person that I am today. Years following my surgery, I do not feel limited to any physical activity. I have gone parasailing, zip-lining, kayaking, snorkeling, snowboarding, and have even sky dived. Today, I am on a new and exciting career path. I am studying to become a Radiologic Technologist and am doing my first clinical rotation at Rady Children's Hospital. Now, instead of being the patient with scoliosis getting her x-rays taken, I do x-ray exams on patients who have scoliosis! It has been so amazing to be able to experience the other side of this process. **Eleven years** following my surgery, I cannot imagine how my life would be had I not had it.

POSTERIOR SURGICAL CORRECTIONS

Pre-Operative Spine



Post-Operative Spine



HEALTHY BACK TIPS

Standing with one foot in front of the other and your knees slightly bent relieves pressure on your lower back. So does sitting with your knees slightly higher than your hips!

FOLLOW US ON



You can share your stories with Setting Scoliosis Straight! We'd love to profile your story in a future edition of Ahead of the Curve. If you'd like to share your individual journey with other patients, please send an email to: mmarks@ssshsg.org.

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HSG RESEARCH GRANT SUBMISSIONS

Part of what is currently missing from spinal research is extensive information on **long-term outcomes** for **adolescent patients** who have corrective spinal surgery. This is why we need patients like Lisa Tran, and all other patients who can come back for their follow-up appointments, to do so. Long term visits are not only the hardest to keep, they are very crucial because they allow us to see the long-term effects of spinal surgery and how various procedures influence patient outcomes as they move into their adult lives.

At the beginning of March, the Harms Study Group submitted three grant proposals to the **Orthopaedic Research and Education Foundation**. These research funding proposals were:

1. Prospective Multi-Center Analysis on 3D Factors Involved in the Decision to Perform a Selective Vs. Non-selective Fusion in AIS.
2. Non-Operative AIS Outcomes—Prospective Evaluation of Surgically Eligible AIS Patients Who Choose Not to Have Surgery.
3. Long Term (≥ 10 Year) Follow-up After Spinal Fusion of Patients with AIS.

STAYING ON TRACK: HSG INVOLVEMENT IN SCIENTIFIC MEETING!



In keeping with tradition, HSG has submitted a total of thirty-eight abstracts for 2012's Scoliosis Research Society & International Meeting on Advanced Spine Techniques meetings.

In February of 2012, members of the Harms Study Group traveled to India and gave presentations at the Association of Spine Surgeons Annual Meeting in New Delhi.

From left to right: Dr. Harry Shufflebarger, Dr. Suken Shah, Dr. Munish Gupta, Dr. Larry Lenke & Dr. Peter Newton.

Q & A WITH HSG SURGEON MEMBER DR. BURT YASZAY FROM SAN DIEGO

Q: Why are girls more likely to get scoliosis?

A: Girls are at greatest risk of developing progressive adolescent idiopathic scoliosis (AIS). Depending on the study, spine curves in the lowest ranges (10 degrees) are nearly equally distributed between boys and girls. Curves of these magnitude are barely considered scoliosis and usually do not require treatment or lead to problems. Scoliosis that requires surgery, however, affects girls more than boys about 7-8 to 1. The exact cause for AIS is not known. Genetics, or the information in our genes, are thought to have a significant influence. The gene or genes involved may be more common to girls or more easily passed through generations in girls. Other possibilities are that certain hormones may be important in the progression of scoliosis. Research is being actively done to answer many of these questions.



Q: I had my surgery a long time ago. Is the same procedure I had done ten years ago still being used today?

A: The principles behind surgery are similar to ten years ago. Depending on the exact surgery, it is possible that you would have a different procedure. Ten years ago, many of the surgeries were performed on the front of one's spine. This meant that for a thoracic scoliosis, the surgery would be done through the chest. This could either be done through a multiple small incisions with a scope or through one larger incision. Some procedures were done through the middle of the back, especially if the procedure need to be done for both the thoracic and lumbar spine. Majority of the procedures (greater than 90%) today are done only through the back. We now commonly use screws to attach the rods to the spine from the back. Tens years ago, if the surgery was from the front, we would have used screws. However if the surgery was from the back, many surgeons were using hooks. The transition to the use of screws in the back has allowed for greater control of the scoliosis. It has allowed us to treat even bigger scoliosis that would normally have required a procedure from both the front and back of the spine to be done only from the back. In general, there has been a decline in the need to go to the front of the spine to treat adolescent idiopathic scoliosis.

REMEMBER, as a patient volunteer in Harms Study Group research, you can continue to help. *Be sure to make all of your scheduled follow-up appointments with your spine surgeon.* Once you have agreed to participate in HSG research, the follow-up information that you provide is CRITICAL to our success in answering our important research questions.

THE SETTING SCOLIOSIS STRAIGHT FOUNDATION IS A NONPROFIT ORGANIZATION WHICH PROVIDES SUPPORT TO THE HARMS STUDY GROUP: A COLLABORATIVE COHORT OF WORLD-WIDE DISTINGUISHED SURGEONS DEDICATED TO THE ADVANCEMENT OF TREATMENT FOR CHILDREN AND ADOLESCENTS WITH SPINE DEFORMITY. TO LEARN MORE OR HELP SUPPORT OUR RESEARCH AND EDUCATIONAL EFFORTS PLEASE VISIT OUR WEBSITE,

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