

AHEAD OF THE CURVE

THE OFFICIAL NEWSLETTER OF SETTING SCOLIOSIS STRAIGHT

The Setting Scoliosis Straight Foundation is a non-profit corporation founded to advance the understanding of scoliosis. The foundation fosters patient education, physician education and multi-center clinical research.

PLEASE REMEMBER! As a patient volunteer for the **Harms Study Group**, your continued help is essential.

Be sure to make all of your scheduled follow-up appointments with your spine surgeon.

The follow-up information that you provide is **CRITICAL** to our success. **YOU** help us answer important research questions.

Thank you for your participation!

WE'VE GONE MOBILE

Our site is now 100%
iPhone, iPad, & Android
Compatible!



Use your mobile device's bar-code scanner app to scan the QR code and see for yourself.

Highlights from the HSG Annual Meeting

On January 2nd, the HSG Executive Committee (comprised of Peter Newton, Harry Shufflebarger, Randy Betz, Amer Samdani, David Clements, and Michelle Marks) met to develop strategic planning, research direction, and study group development.

On January 3rd, eleven of the thirteen members of the Setting Scoliosis Straight's Board of Directors met to discuss fundraising and outreach efforts for the foundation. Plans to celebrate the Harms Study Group's twenty years of existence were introduced.

On January 4th—5th, surgeon members of the Harms Study Group, and associated colleagues, met to discuss the findings of the latest research conducted by the study group. "The Future of Adolescent Idiopathic Scoliosis (AIS)," which was moderated by Randy Betz and Amer Samdani, invited speakers to share their vision for future research and innovative treatment of AIS. Many ideas relating to 3D spine reconstruction in the AIS population will be implemented within the study group in the coming year.



HSG
HARMS STUDY GROUP
Pioneering Research in Spinal Deformities

*Anything the Mind Can
Conceive & Believe,
It Can Achieve.*

A Quick Flashback: The Year in Review

Adolescent Idiopathic Scoliosis (AIS) in 2012

- 328 of 3,325 patients were enrolled in 2012
- 43 abstracts were presented from this study
- 13 manuscripts were published in peer reviewed journals

Cerebral Palsy Scoliosis (CP) in 2012

- at the year's end, a total of 253 operative patients were enrolled
- at the year's end, a total of 67 non-operative patients were enrolled
- 3 abstracts were presented from this study
- 1 abstract was nominated for a Hibbs Award by the Scoliosis Research Society

Scheuermann's Kyphosis (PSK) in 2012

- at the year's end, a total of 123 operative patients were enrolled
- at the year's end, a total of 23 non-operative patients were enrolled
- 4 abstracts were presented from this study

Post-op Motion in 2012

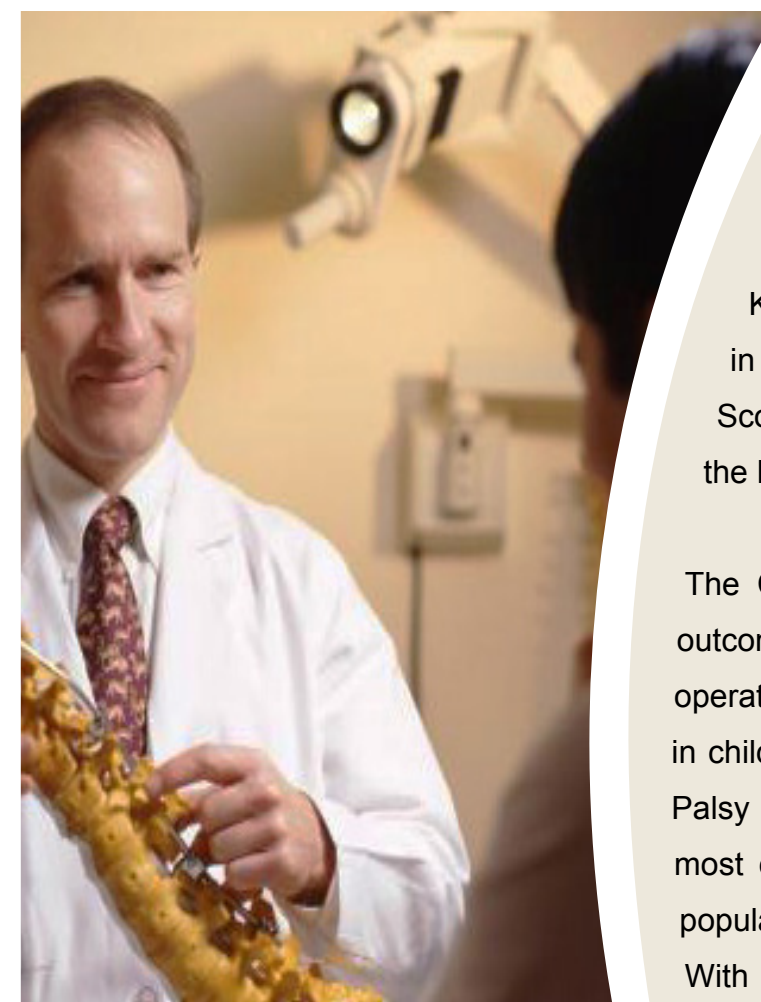
- at the year's end, 281 patients were enrolled
- by the end of 2013, a goal of 300 patients will be met

The AIS Patient Handbook

- Mandarin, Spanish, and Turkish translations are complete
- Arabic and French translations are in process
- 3,422 copies have been sold to date

Moving Forward

We would like to take this time to thank all of our supporters who donated to us in 2012. Due to the success of the foundation's efforts to raise funds for the Harms Study Group, two research efforts will be internally funded in 2013. Increased enrollment for our prospective Cerebral Palsy study will be internally funded, and the initiation of a study on post-spinal fusion pregnancies in the Adolescent Idiopathic Scoliosis population will be implemented. While our fundraising efforts in 2012 were sufficient enough to help us begin this study, continued support will allow us to complete it, so please take a moment to visit our donation page and make a pledge today.



JOHNS HOPKINS
M E D I C I N E

A Site Highlight: Baltimore

Dr. Sponsellor and his site coordinator, Leslie Thaxton, have assisted with HSG research since 2004 by participating in the Adolescent Idiopathic Scoliosis, Scheuermann's Kyphosis, and Cerebral Palsy Scoliosis studies. Although the Baltimore site participates in three HSG studies, Dr. Sponsellor is the Lead Investigator for HSG's Cerebral Palsy Scoliosis (CP) study, and this is what the Baltimore site is best known for.

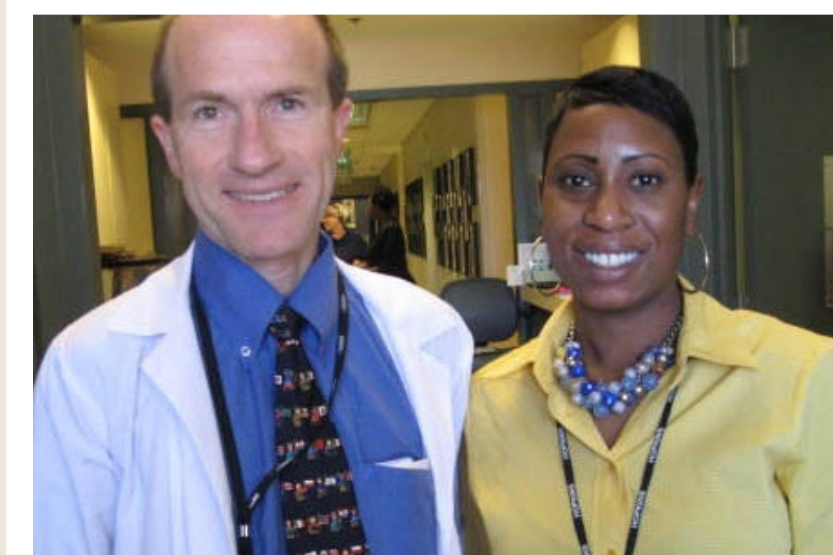
The CP study's focus is on evaluating outcomes of operative versus non-operative treatment of spinal deformities in children with Cerebral Palsy. Cerebral Palsy patients are very fragile, so the most effective form of treatment for this population also needs to be the safest. With Dr. Sponsellor at the lead, HSG is studying various surgical techniques and evaluating the rates of complications

associated with spinal surgery in this delicate population. In 2012, Dr. Sponsellor presented a podium at SRS on wound infections following spinal fusion in scoliosis patients with CP.

At the time of this printing, twelve sites have contributed to our CP study and a total 271 operative patients, and approximately 70 non-operative patients, have been enrolled.

Baltimore has contributed data for 49 operative patients and 17 non-operative patients. Enrollment in our CP study is ongoing through 2013.

We fully expect Baltimore to continue leading the way in our landmark CP study and want to take a moment to thank the entire Baltimore team.



Patient Story Amanda Kupiec

One of the most common questions spinal fusion patients are asked is how their surgery has changed or affected their lives. In 2007, Amanda had her scoliosis corrective surgery at the age of thirteen. Amanda's spinal fusion left her with two twenty inch rods and eighteen screws in her back. Though her surgery was extensive, and her recovery was difficult, Amanda used this time to learn more about herself. It was during her recovery that Amanda discovered her love of baking. As Amanda said, "Baking helped me to ease my mind from the pain and focus on the positive."

Amanda's newfound passion for baking not only helped her make it through her recovery, it also shaped the entire trajectory of her life. Currently, Amanda is attending the Culinary Institute of America in Hyde Park, New York, where she is pursuing a Bachelor of Arts degree in Baking and Pastry Arts, and she has also helped spawn a very successful family business called Kuplicakes & Co.

In case you were wondering how Amanda's physical recovery following her spinal surgery has progressed, now would be a great time to let you know that Amanda plays competitive club volleyball, she water skis, and she snowboards. Since her surgery, Amanda has also completed three half marathons and three triathlons. In other words, Amanda is doing great!





Supporting Discoveries in Spinal Deformities

We want to hear from you!

If you have any questions for a **surgeon member** of our team, are a **grateful patient** with a **story to share**, or would like your site to be highlighted in an upcoming newsletter, please contact **Michelle Marks** at mmarks@ssshsg.org.

We look forward to hearing from you!

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FROM RIB HUMP TO BABY BUMP

We have just launched our new pregnancy in AIS study!
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Click the "Like" button on Facebook.

Sign up to follow us on Twitter.

We will randomly pick one winner from Facebook and one winner from Twitter on June 30th, 2013. Stay tuned!

Winners will be announced on our Facebook and Twitter pages.



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