

setting
SCOLIOSIS
straight

Supporting Discoveries in Spinal Deformities

# **HSG**HARMS STUDY GROUP

Pioneering Research in Spinal Deformities

### A LETTER FROM THE CHAIRMAN



Dear Friends and Family of the Setting Scoliosis Straight Foundation and The Harms Study Group,

First and foremost, we thank you for your passionate support for our efforts to change lives for the better. Every year I am touched by patients and families who share how much their scoliosis treatment has lifted a burden and freed them to live active and productive lives.

We are beginning the 20th year of The Harms Study Group. It is with great pride that we recognize two of the most influential individuals whose vision created this research group in 1995. We thank Professor Jürgen Harms and Mr. Lutz Biedermann for their creativity, dedication, and unwavering support to improve scoliosis treatment.

Our research teams are continually striving to discover new ways to make scoliosis treatments easier, safer and more reliable. "Quality" in healthcare is sometimes difficult to measure, but in the field of scoliosis, Setting Scoliosis Straight is supporting The Harms Study Group's efforts to establish what "quality" really means for our spinal deformity patients.

We remain indebted to all patients, researchers and sponsors who continue to help us reach new heights of discovery. Together we can cure scoliosis and change for the better those whose lives are affected by spinal deformity.

Peter Newton, MD

Othe leads

President, Setting Scoliosis Straight Foundation

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SCOLIOSIS, or curvature of the spine, can be a devastating diagnosis for a child or adolescent. It affects almost 3% of, or an estimated 6 million, people in the United States alone. The diagnosis is usually made between the ages of 8 – 15, at or near the onset of puberty. Each year, hundreds of thousands of children are put into a brace for scoliosis and 38,000 undergo spinal fusion surgery. In spite of extensive research efforts, adolescent scoliosis remains idiopathic, which means the cause is unknown. Scientists have identified that Idiopathic Scoliosis is a genetic condition.



and they continue to work to discover the combination of individual genes that cause scoliosis. Stopping the progression of scoliosis prevents significant health issues associated with severe scoliosis – pulmonary and organ compromise, neurological complications, and muscular pain. Surgical correction of scoliosis changes lives. Normalizing appearance and preventing the progression of the deformity are the goals that motivate orthopaedic surgeons who seek to return children back to a long term active life.

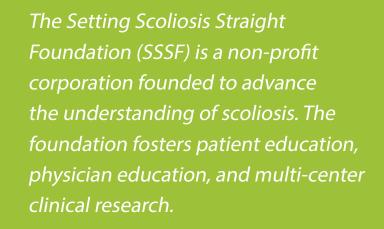
Katie Lyons' ultimate goal was to live the life of an athlete. Surgery to correct Adolescent Idiopathic Scoliosis did not prevent her from competing nationally as a skier while in college. The experience was so positive that Katie has entered medical school with a new goal of specializing in orthopaedics.

# INTRODUCTION





Supporting Discoveries in Spinal Deformities



### INTRODUCTION

The mission of the Setting Scoliosis Straight Foundation is to advance the treatment of scoliosis and spinal deformity for children through research and education.

### **BOARD OF DIRECTORS**



Peter Newton, MD Chairman/ President



Dave Clements, MD Treasurer



Michelle Marks, PT, MA Secretary



Harry Shufflebarger, MD



Amer Samdani, MD



Baron Lonner, MD



Suken Shah, MD



Randy Betz, MD



Tom Errico, MD



Robert Stone



Alvin Crawford, MD



Sally Lynch



Kevin Sayar



Stacey Stevens

""Through leading clinical research, patient education, and caring physicians, the Setting Scoliosis Straight Foundation helps children and adolescents with scoliosis reach their full potential."

### HARMS STUDY GROUP HISTORY

# THE HARMS STUDY GROUP: A Brief History

In 1995, a collaborative group of surgeons formed to study the outcomes of surgical correction of adolescent idiopathic scoliosis (AIS). The group was created by Randal Betz, MD, of Philadelphia and **Professor Jürgen Harms, MD**, of Germany. A total of five surgeons were involved in the group at its beginning. The initial collaboration focused on the comparison of anterior versus posterior corrective approaches in patients with AIS. From

1995 to 1998, the group developed initial protocols and radiographic measurements needed to establish future prospective studies.

Though much has been accomplished by The Harms Study Group in the subsequent years, initiating a multi-center research group of this magnitude was no small feat. The leadership and vision of Professor Harms was invaluable in poising this group to achieve incredible accomplishments, and the success of the initial study group's effort was made possible by the generous seed grant funded by **Mr. Lutz Biedermann.** 



Professor Jürgen Harms, MD:

Founding member of The HSG and Chief of Spine Surgery at Ethianum Klinik, Heidelberg.

#### Lutz Biedermann:

President of Biedermann Motech and establisher of The Max Biedermann Institute for Biomechanics.



### CELEBRATING 20 YEARS OF RESEARCH

#### 20 YEARS OF RESEARCH FUELING THE NEXT 20 YEARS OF INNOVATION

In 2015, The Harms Study Group will turn twenty, and the study group's anniversary will be commemorated via educational and fundraising events that will be held in Las Vegas.

#### **EDUCATION:**

"Evidence Based Pediatric Spinal Deformity Care" will be held at the Bellagio on January 24th, 2015. This one day Continuing Medical Education (CME) course will feature a roster of world class surgeons who will present master's lectures, lead panel discussions, and moderate debates. Harry Shufflebarger, MD, is the Course Chairman.

#### **FUNDRAISING/AWARENESS:**

On the evening of January 24th, 2015, the 20th Anniversary Fundraiser/Awareness Gala will be held at the Gehry Building. This event will include inspirational patient stories, highlights of HSG achievements, and live as well as silent auctions. Suken Shah, MD, is the Gala Chairman.

Please save the date of **January 24th, 2015!** Our CME course and fundraising/awareness events will be held on that day in Las Vegas, Nevada. We hope to see you all there!

Larry Ruvo (pictured far right) is both a mentor to and supporter of The Harms Study Group. The 2015 fundraising gala will be held at the Lou Ruvo Center for Brain Health in the Gehry Building (pictured near right).



# 20 YEARS OF RESEARCH

### FUELING THE NEXT 20 YEARS OF INNOVATIONS

















1995

1997

2000

2002

2004

Founding of The Harms Study Group by Randal Betz, MD and Professor Jurgen Harms, MD

Seed grant funded by Mr. Lutz Beidermann

Initial study protocols and radiographic measures developed Initial data collection begins

Publications and classification system established

Formal multi-center study group funding received from DePuy Orthopaedics

Peter Newton, MD and Randal Betz, MD develop multi-user, web-driven scoliosis database

AIS protocols formalized and Lenke 1 study launched Implementation of standardized data collection practices

Organized individual member database mining projects conducted

Research surgeons grow from 12 to 16 members

AIS database volume becomes largest in existence

First multicenter retrospective study of Scheuermann's Kyphosis completed

Three multicenter retrospective studies are performed:
1) The use of Single Lung Ventilation
2) Retrospective CP Scoliosis
3) The Results of Three Classes of Surgical Treatment for Congenital Scoliosis Due to Hemivertebrae

Prospective study of Scheuermann's Kyphosis is launched











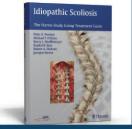














2012 2013



2008

2010

Prospective study of Post-Operative Motion Preservation in AIS is launched

Retrospective studies of Comparison of Severe Scoliosis Treated With or Without Halo Traction is performed

Study Group contributions at scientific meetings grows to 15 podium presentations

Completion of the Lenke 1 Curve Study and the Algorithm Study is converted into a Long-term Database Registry of AIS

The Retrospective Study of Posterior Vertebral Column Resection in Pediatric Spinal Deformity is successfully completed

The Harms Study Group Foundation, a non-profit 501(c)(3) corporation, is formed to support the research efforts of The Harms Study Group

The Prospective Study of Scoliosis in Children with Cerebral Palsy is launched

The Retrospective Study of Scoliosis Correction in Marfan Syndrome Patients' is successfully launched

The textbook "Idiopathic Scoliosis: The Harms Study Group Guide to Evaluation and Treatment" is published

First research fundraising effort results in donations that exceeded \$100K to support HSG research and education mission

Research grant is received from SRS to study 10 year postoperative motion outcomes

The patient education handbook "AIS; **Navigating Your** Journey" is published

The 3000th patient is enrolled in the prospective AIS database registry study A scientific meeting for the Scoliosis in Cerebral Palsy Study is held through a grant from **OREF** 

The Harms Study **Group Foundation is** rebranded and becomes **Setting Scoliosis** Straight

The first non-gala fundraiser for Setting Scoliosis Straight generates over \$25K for spinal deformity research and education

The patient education handbook is translated into Chinese and Spanish

Prospective Study of Scheuermann's Kyphosis is successfully completed

Prospective evaluation of Post-Operative Motion in AIS (2-5 year follow) is successfully completed

Retrospective study of pregnancy in AIS is launched

The patient education handbook is translated into Turkish and Latin American Spanish

### RESEARCH PRODUCTIVITY

HARMS STUDY GROUP YEARLY PRODUCTIVITY				
Year	Podium Presentations*	Poster Presentations*	Manuscripts Published^	
2000	8	10	8	
2001	5	5	8	
2002	6	8	6	
2003	7	5	6	
2004	9	3	8	
2005	7	17	6	
2006	5	12	2	
2007	20	49	7	
2008	20	31	11	
2009	26	24	13	
2010	28	26	6	
2011	27	34	14	
2012	23	27	12	
2013	22	16	14	

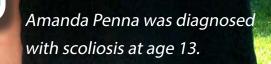
\*Total at AAOS, POSNA, IMAST, SRS, AACPDM, AAP, NASS; ^ in total peer reviewed journals

The Setting Scoliosis Straight Foundation and The Harms Study Group are strongly committed to educating others about adolescent spinal deformity. By sharing our research findings with health care providers and surgeons at international medical conferences and in international scientific journals, we can impact and improve the level of care for children with spinal deformities across the entire globe.

In 2013, The Harms Study Group presented a total of thirty-eight podiums and posters at medical conferences, and our members had a total of fourteen manuscripts published in scientific journals. This is The Harms Study Group's highest number of published manuscripts in a year, so we wish to congratulate the hard work of our team!

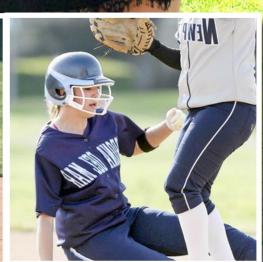


A healthy, pain-free body is essential for all athletes, but by the time Amanda Penna reached eighth grade, her scoliosis had become so painful that it was affecting her performance. Amanda's spine surgery turned a seventy-eight degree curve into an eighteen degree curve, and thanks to her surgery she managed to grow three inches, improve her game, and begin living a life free of back pain!









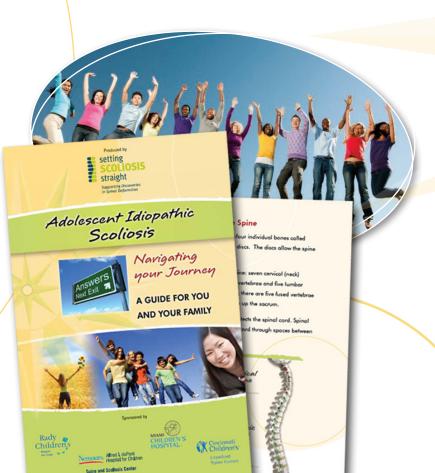


### **HANDBOOK**

# "NAVIGATING YOUR JOURNEY" IS AN EDUCATIONAL GUIDE FOR PATIENTS AND FAMILIES

Being diagnosed with Adolescent Idiopathic Scoliosis can be very frightening and confusing for young patients. The amount of information they receive with a diagnosis is vast, and a tangible source of knowledge can be a very useful thing. Throughout the years, many Harms Study Group patients expressed the desire to have a resource to read when they received their initial diagnosis, but prior to 2010, a resource written by the leaders in the field did not exist.

In late 2009, The Harms Study Group began production on an Adolescent Idiopathic Scoliosis patient education handbook, and the first version of this patient education handbook was circulated in 2010. At the time, 500 copies were printed and circulated to patients and their families, health care providers, and surgeon colleagues. In the two years that followed, feedback was solicited on how this handbook could be improved, and in 2012, the second version of our patient education handbook was completed.



#### WHAT WE HAVE ACCOMPLISHED

- Through sponsorship funds we were able to print 15,000 copies of version two, which are now being circulated throughtout the United States and other English-speaking countries.
- More than 10,000 copies have been distributed worldwide.
- Our handbook has been translated to Chinese, Turkish, and two Spanish versions.
- Translations into French and Arabic are underway.

### SCHEUERMANN'S KYPHOSIS STUDY

Scheuermann's Kyphosis is a spinal deformity often diagnosed during adolescence. Patients with this disorder have back pain, a back deformity, and in severe cases, restrictive lung disease. Dr. Baron Lonner, a surgeon member of The Harms Study Group since 2004, served as the primary investigator for a first-of-its-kind study regarding this spinal deformity. A total of 123 operative and 23 non-operative patients participated in the study, which launched in 2006 and finished enrollment in 2010. A few goals of this study included exploring the impact of kyphosis surgery on pulmonary function, comparing treatment approaches on both surgical and non-surgical patients, and defining clinical presentation of the deformity.





Study Findings: Surgery for Scheuermann's Kyphosis in the adolescent population results in significant improvements in Health Related Quality of Life.



Baron Lonner, MD
has dedicated
eight years to the
successful completion
of this prospective,
multi-center study.

# SCHEUERMANN'S KYPHOSIS STUDY

Our Scheuermann's Kyphosis Study aimed to improve care for patients diagnosed with this deformity. In 2011, eight abstracts were presented at scientific meetings with findings showing that kyphosis has a significantly negative impact on adolescents' quality of life and that complication rates are increased in patients with kyphosis as opposed to patients with Adolescent Idiopathic Scoliosis.

By 2012, a total of fifteen abstracts had been generated with conclusive data indicating that

hypo-lordosis was correlated with increased pain in kyphosis patients and that changes in patient height following spinal surgery depend on the preoperative magnitude of the deformity. Finally, by 2013, a total of nineteen abstracts had been presented with findings showing that pulmonary improvement and a better quality of life follow surgical intervention for patients with Scheuermann's Kyphosis. Patient follow-up data was completed in December 2013.







Post-operative

### CEREBRAL PALSY STUDY

In 2008, The Harms Study Group launched a Prospective Study of Scoliosis in Children with Cerebral Palsy (CP), led by primary investigator, Paul Sponsellor, MD, from Baltimore. Since 2008, our research sites have enrolled 325 operative patients and 93 non-operative patients in this study. All patients are followed for two years from their surgery or baseline visit.

Preliminary results from this study have found that antifibrinolytic use substantially reduces blood loss during surgery in this patient population. We observed notable health differences between patients who were treated operatively and those who were treated non-operatively. All of these findings were shared with healthcare providers and fellow surgeons at international conferences and meetings.

A huge strength of this study lies within its use of numerous health related quality of life tools. These allow us to assess the outcome of treatment for both the patient and the patient's primary caregivers. The ability to specifically inquire about the day-to-day impact treatment is having allows us to further our understanding of various treatments and their outcomes as well as select the appropriate treatment type for each patient.

Future goals for this study include extending follow-up data to a five year collection point so that longer term outcomes can be better understood and continuing enrollment in our database so we have a larger patient population to fuel our research.

Patient With Scoliosis Pre-Operative

PA X-ray of Cerebral Palsy



Post-Operative



### **CP PATIENT STORY**



Isabel was born prematurely at twenty-nine weeks and was later diagnosis with Cerebral Palsy. She has been under the care of Dr. Mark Abel since 2001. As Isabel continued to grow, her spine curvature did too, and soon it was causing her discomfort and negatively impacting her quality of life. Isabel had to have multiple surgeries to fix both kyphotic and lordotic curves in her back, but after six months of recovery time, Isabel's family is able to see astonishing improvements in Isabel's daily life. Her pain has lessened, her sleep has improved, she is able to take less medicine, and she can face forward to see who she is

interacting with. Also, due to Isabel's increased lung capacity, her speech has improved, and her parents are able to hear her say things that she couldn't before. The Holmes are very happy with Isabel's spinal surgery.

"We are so grateful to see these changes in her life. I think we got excellent guidance as well as surgical expertise and care. Thank you, Mark Abel. We owe you so many thanks for your help in bringing back Isabel's smile."

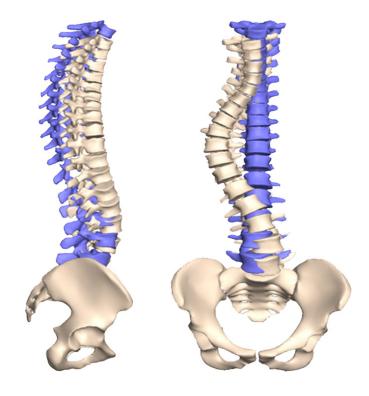
### 3D EVALUATION OF AIS

### SPINAL FUSION: 3D RECONSTRUCTION AND LEVEL SELECTION

The basic radiographic index of scoliosis severity has long been the Cobb Angle, which is a 2D measurement taken from a x-ray image of the patient's spine. This 2D image has not only been the basis in deciding whether or not spinal fusion should occur, but it is also the prime indicator in selecting proper levels of instrumentation for spinal fusion candidates. Selecting the proper levels of fusion is of utmost importance as the ultimate goal for surgical treatment is to maximize curve correction while maintaining mobility in the unfused spinal segments.

While it has long been understood that Adolescent Idiopathic Scoliosis is a 3D rotary deformity of the spine, the ability to view the deformity in 3D has been limited to date. Only being able to view a 3D deformity in a 2D manner prior to fusion has produced serious knowledge gaps in scoliosis treatment. However, with The Harm Study Group members of Montreal St. Justine leading the efforts, a practical solution allowing for 3D reconstruction of pre-operative patient spines is being adopted into clinical and research practice.

Scoliosis has always been a three-dimensional spinal deformity, but until recently, approaches to surgical correction of scoliosis have all been based on two-dimensional radiographic data. With members of The Harms Study Group leading the way, this is changing.



### 3D EVALUATION OF AIS

### THE FUTURE OF AIS ASSESSMENT AND TREATMENT

Through the collaboration of the Montreal St. Justine Orthopedic Research Team and the research support from EOS Imaging, The Harms Study Group is poised to be at the forefront of answering many important clinical scoliosis questions with 3D data. Most significantly, a computer model of various surgical treatment scenarios may be implemented to help surgeons discern the best levels of fusion for each patient. This individual based treatment assessment and treatment execution is the future of surgical correction in AIS.





EOS Imaging has launched the EOS system which provides high-quality, whole-body images of a sitting or standing patient using a fraction of the radiation dose required by conventional imaging methods. It uses simultaneous image acquisition from two connected imaging assemblies enabling intrinsic 3D weight bearing modeling in just two views. The system is now in place in the majority of The Harms Study Group Research Sites.



### DATABASE USER PROGRAM

### SETTING SCOLIOSIS STRAIGHT DATABASE USER PROGRAM

In 2011, Setting Scoliosis Straight launched its Database User Program. This program is designed to promote systematic data collection on spinal deformity patients worldwide. Our Database User Program gives surgeons a viable research tool and works as a quality improvement initiative.



Our program assists surgeons interested in collecting systematic data on AIS patients and facilitates improvement in care and surgeon collaboration.



#### **RESEARCH TOOL:**

- Our program facilitates surgeon collaboration and data collection for the purpose of research production.
- Our program provides standardized research protocols and case report forms.
- Individual sites are established in our database for easy data entry and extraction.

#### **QUALITY IMPROVEMENT INITIATIVE:**

- Our program helps surgeons define how their quality and safety measures compare with those of their peers.
- Leverage is gained from the expertise and experience of the most successful multicenter spinal deformity research group in existence.

### GRATEFUL PATIENT

Kathy Riciardi underwent spinal surgery in 2009. Kathy, who was and is an avid dancer, experienced physical pain and emotional distress after her surgery. At a time when most girls were simply looking forward to their oncoming senior year of high school, Kathy was faced with a long recovery, but she never gave up. Since her surgery, Kathy has made a spectacular recovery, and she has donated an extraordinary amount of her time and effort to improving the lives of others in as many ways as she can.

Kathy is utilizing her drive to make a difference in this world by helping other young patients with scoliosis. She has orchestrated two fundraisers with the proceeds benefiting The Setting Scoliosis Straight Foundation to help with the production of our AIS patient handbook. We are grateful for all of Kathy's drive and efforts!



Grateful Patient Kathy
Riciardi fundraises
for Setting Scoliosis
Straight with her
Griffin Muddness
Tug-of-War campaign



## **VOLUNTEERS**

Lena was diagnosed with scoliosis at age seven, and in 2010 she had a spinal fusion surgery. Dr. Peter Newton successfully performed Lena's surgery, and on her fourteenth birthday Lena was released from Rady Children's Hospital in San Diego. Lena's spine surgery taught her how important it is to have helpful people in one's life during difficult times, and the support she received



during her recovery inspired her to find ways to help others. Lena volunteers at Setting Scoliosis Straight's San Diego office once a week. She also appeared in our educational patient handbook. Lena plans to become a pediatric nurse so she can continue to positively impact others' lives. We're so grateful for Lena's help, and we're excited to see where her passion for helping others will take her!

Noreen Gaynor moved to California in 2009, and she has been volunteering with Setting Scoliosis Straight since 2010. Her daughter, Tracey Bastrom, is The Harm Study Group's statistician. Noreen has focused her efforts on data entry, and we thank her for all of the time she has donated!

Roxy Gil began volunteering for Setting Scoliosis Straight in 2013. She is a two time cancer

survivor who discovered she had a moderate "case"

of scoliosis during her treatment. She is also our Executive Director, Michelle Mark's, former 6<sup>th</sup> grade teacher! Roxy says it is an honor to have had Michelle in her class and to be able to volunteer for Setting Scoliosis Straight, and we thank her for her efforts!



### INFRASTRUCTURE

Setting Scoliosis Straight's infrastructure is committed to excellence in research quality and productivity. Our core infrastructure performs central data coordination which includes obtaining Internal Review Board approval, tracking Informed Consents, acquiring images, measuring x-rays, and performing data QA. They also oversee project management, database management, and site management. Additionally, the infrastructure manages foundation finances, site contracts, and foundation development.

#### STAFF:

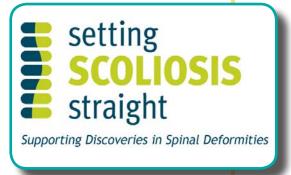
Amy Bartley, BA – Assistant Developer/ QA Manager
Evan Xanthos BS, MS – SSSF Research Assistant
Harvey Ly, BS – SSSF Webmaster/Assistant Developer/ Central &
Backlogs X-ray Measurer
Jon Marie Basel – SSSF Contracts & Finance Administrator
Maty Petcharaporn, BS – SSSF SD Team Manager/
Co-Research Director
Michelle Marks, PT, MA – SSSF Research and Executive Director
Sierra Abate, MSTOM – SSSF Research Assistant

Our effort to raise funds to support scoliosis research allows us to continue to advance scoliosis treatment for patients worldwide.

By purchasing our products you will be supporting our research and further helping us help children with scoliosis.

Tracey Bastrom, MA – SSSF Statistician









### 2013 SCIENTIFIC PUBLICATIONS

#### AIS DATABASE REGISTRY:

#### Published:

- Hwang SW, Samdani AF, Lonner BS, Marks MC, Bastrom TP Betz RR, Cahill PJ. A Multi-Center Analysis of Factors Associated With Change in Height After AIS Deformity Surgery in 447 Patients. J Neurosurg Spine. 2013 Mar;18(3):298-302.
- Lark RH, Yaszay B, Bastrom TP, Newton PO. Adding Thoracic Fusion Levels in Lenke 5C Curves: Risks and Benefits. Spine. 2013 Jan 15;38(2):195-200.
- 3. **Newton** PO, Marks MC, Bastrom, TP, Betz R, Clements D, Lonner B, Crawford A, Shufflebarger H, O'Brien M, Yaszay B; Harms Study Group. Surgical Treatment of Lenke 1 Main Thoracic Idiopathic Scoliosis: Results of a Prospective Multicenter Study. Spine. 2013 Feb 15;38(4):328-338.
- Demura S, Yaszay B, Batrom TP, Carreau J, Newton P, Harms Study Group. Is Decompensation Preoperatively a Risk in Lenke 1C Curves? Spine (Phila Pa 1976). 2013 May 15;38(11):E649-55.
- Trobisch P, Samdani AF, Betz RR, Bastrom TP, Pahys JM, Cahill PJ: Analysis of Risk Factors for Loss of Lordosis in Patients Who Had Surgical Treatment With Segmental Instrumentation for Adolescent Idiopathic Scoliosis. Eur Spine J. 2013 Apr 9.
- McElroy, MJ, Sponseller, PD, Fuhrhop, SK, Russell, Newton, PO, Marks, MC, Sanders, JO, Yazici, M, Pawelek, JB, Akbarnia, B, The Harms Study Group and the Growing Spine Study Group. Operative Idiopathic Early Onset Scoliosis and Adolescent Idiopathic Scoliosis Curves Have Different Characteristics. Spine 2013;38(16):1368-1374.
- Hwang SW, Samdani AF, Stanton P, Marks MC, Bastrom T, Newton PO, Betz RR, Cahill PJ. Impact of Pedicle Screw Fixation of Loss of Deformity Correction in PatientsWith Adolescent Idiopathic Scoliosis. J Pediatr Orthop. 2013 Jun;33(4):377-82.
- Miyanji F, Samdani A, Ghag A, Marks M, Newton PO (2013) Minimally Invasive Surgery for AIS: An Early Prospective Comparison With Standard Open Posterior Surgery. J Spine 2013,

- S5 http://dx.doi.org/10.4172/2165-7939.S5-001.
- Monazzam, S, Newton, P, Batrom T, Yaszay, B, Harms Study Group: Multi Center Comparison of the Factors Important in Restoring Thoracic Kyphosis During Posterior Instrumentation for Adolescent Idiopathic Scoliosis. Spine Deformity Journal Vol 1 Issue 5 (2013) 359-364..
- Marks, MC, Newton, PO, Bastrom, TP, Petcharaporn, M, Betz, RR, Sponseller, PD, Lonner, B, Shah, SA, Shufflebarger, H, Harms Study Group. Surgical Site Infection (SSI) in Adolescent Idiopathic Scoliosis Surgery. Spine Deformity Journal Vol 1 Issue 5 (2013) 352-358.
- Bastrom TP, Marks MC, Yaszay B, Newton PO; Harms Study Group. Prevalence of Postoperative Pain in Adolescent Idiopathic Scoliosis and the Association With Preoperative Pain. Spine. 2013 Oct 1;38(21):1848-52. doi: 10.1097/BRS.0b013e3182a4aa97.
- 12. Samdani, AF, Belin EJ, Bennett JT, Pahys JM, Marks MC, Miyanji F, Shufflebarger HL, Lonner BS, Newton, PO, Betz RR, Cahill PJ. Unplanned Return to the Operating Room in Patients With Adolescent Idiopathic Scoliosis: Are We Doing Better With Pedicle Screws? Spine. 2013 Oct 1;38(21):1842-7.
- Demura S, Bastrom TP, Schlechter J, Yaszay B, Newton PO;
   Harms Study Group. Should Postoperative Pulmonary Function
   Be a Criterion That Affects Upper Instrumented Vertebra Selection
   in Adolescent Idiopathic Scoliosis Surgery? Spine. 2013 Oct
   15;38(22):1920-6.

#### Accepted for publication:

- 1. CAHILL Is There a Role for the 5 Degree Rule in AIS?
- 2. CAHILL Is There a "July Effect" in Surgery for AIS?
- 3. LONNER Body Image in Patients With AIS: Validation of the Questionnaire.
- 4. NEWTON Analysis of Intraoperative Neuromonitoring Events.
- 5. YASZAY Should Shoulder Balance Determine Proximal Fusion?

#### **CP SCOLIOSIS STUDY:**

#### Published:

Sponseller PD, Jain A, Shah SA, Samdani A, Yaszay B, Newton PO, Thaxton LM, Bastrom TP, Marks MC. Deep Wound Infections After Spinal Fusion in Children with Cerebral Palsy: A Prospective Cohort Study. Spine. 2013 Nov 1;38(23):2023-7.

#### SCHEUERMANN'S KYPHOSIS STUDY:

#### Accepted for publication:

- 1. LONNER Pre-Operative Pulmonary Function in Patients With Operative SK.
- LONNER Effect of Scheuermann's Kyphosis Deformity on Adolescent Quality of Life.

# 2013 SCIENTIFIC PRESENTATIONS







Presented at AAOS:

3 PODIUMS
4 POSTERS



Presented at POSNA:

### 2013 SCIENTIFIC PRESENTATIONS







Presented at NASS:

2 PODIUMS



Presented at SRS:

11 PODIUMS

**6 POSTERS** 

Presented at IMAST:

3 PODIUMS

**6 POSTERS** 





Pioneering Research in Spinal Deformities

Setting Scoliosis Straight and The Harms Study Group are key partners in the mission to improve scoliosis treatment around the globe.

The Harms Study Group (HSG) is a worldwide cohort of surgeons who perform comprehensive, multi-center prospective research studies focused on pediatric spinal deformity. The Harms Study Group is the premier multi-center research group for pediatric spinal deformity, with nearly twenty years of productivity.

Through comprehensive, multi-center prospective research studies, questions regarding treatment approach and techniques, to achieve desired outcomes, are studied. All research is done with a commitment to be internationally recognized for the highest quality published research on new spinal deformity surgery techniques.

#### **HSG EXECUTIVE COMMITTEE**



Professor Jürgen Harms, M.D. Chief of Spine Surgery at Klinikum Karlsbad-Langensteinbach, Karlsbad Germany: Professor of Orthopaedic Surgery; Founding Member of The Harms Study Group



Peter O. Newton, M.D.
Chief of the Orthopaedic Division and the Scoliosis Service at Rady
Children's Hospital in San Diego,
California; Clinical Professor of
Orthopaedic Surgery at the University
of California, San Diego; Primary
Coordinator for The Harms Study
Group; SSSF Board Member



Randal R. Betz, M.D.
Chief of Staff and Medical Director
of Spinal Cord Injury Unit at
Shriner's Hospital for Children,
Philadelphia, Pennsylvania; Professor
of Orthopaedic Surgery at Temple
University School of Medicine;
Founding member of The Harms
Study Group; SSSF Board Member



Harry Shufflebarger, M.D.
Director, Division of Spinal Surgery,
Department of Orthopedic Surgery,
Miami Children's Hospital, Miami,
Florida; SSSF Board Member



Amer F. Samdani, M.D. Director of the Spine Service at Shriner's Hospital for Children, Philadelphia, Pennsylvania; SSSF Board Member



Michelle C. Marks, PT, M.A. PT, MA: Research/Executive Director, Setting Scoliosis Straight Foundation; SSSF Board Member



David Clements, M.D.
Professor of Orthopaedic Surgery and
Neurosurgery, Cooper Medical School
of Rowan University; Attending
Surgeon, Shriners Hospital for
Children-Philadelphia Unit; Founding
Member of The Harms Study Group;
SSSF Board Member

"HSG participation permits direct access to many thought leaders in spinal surgery.

HSG research has been important to me in selecting cutting edge treatment options for my patients."

- Harry Shufflebarger, M.D.

#### **HSG CORE MEMBERS**

Core members contribute significantly to the main studies of the group. Membership is by invitation of the Executive Committee.



Baron Lonner, M.D.
Director of Scoliosis Associates, Chief
Division of Spine Surgery Mount
Sinai Medical Center, Beth Israel
Hospital, Professor of Orthopaedic
Surgery, SSSF Board Member



**Firoz Miyanji, M.D.** Spine Surgeon at British Columbia Children's Hospital, Vancouver, British Columbia, Canada



Patrick J. Cahill, M.D. Spine Surgeon at Shriners Hospital for Children— Philadelphia, Pennsylvania



Jack Flynn, M.D.
Associate Chief in the Division
of Orthopaedics at the Children's
Hospital of Philadelphia; Associate
Professor of Orthopaedic Surgery at
the University of Pennsylvania



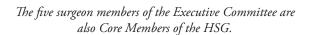
Lawrence Lenke, M.D.
Jerome J. Gilden Endowed Professor
of Orthopedic Surgery; Co-Chief
of Pediatric and Adult Spinal,
Scoliosis, and Reconstructive Surgery,
Washington University—St. Louis
Medical School; Chief of Spinal
Surgery, St. Louis Children's Hospital,
Missouri, SSSF Board Member



Suken A. Shah, M.D.
Division Chief, Spine and Scoliosis
Center at Nemours/Alfred I. DuPont
Hospital for Children in Wilmington,
Delaware; Fellowship Director,
Pediatric Orthopaedic Surgery;
Associate Professor of Orthopaedic
Surgery at Jefferson Medical College
in Philadelphia, Pennsylvania; SSSF
Board Member



**Burt Yaszay, M.D.**Spine Surgeon at Rady Children's
Hospital in San Diego, California;
Clinical Assistant Professor of
Orthopaedic Surgery at the University
of California, San Diego





"The HSG allows the most creative minds and skilled surgeons involved in pediatric scoliosis treatment to dream about what the future might hold for their patients...and then go gather the information to validate their innovations and solutions. Scoliosis care is advanced by this collaborative group at a rate that would not be possible without it."

- Peter O. Newton, M.D.



**Hubert Labelle, M.D.**Professor of Surgery at University of Montreal and Chief of the MSK axis of excellence at CHU Saint-Justine Mother and Child University Hospital Center



Paul Sponseller, M.D. Head of the Division of Pediatric Orthopaedics at Johns Hopkins Hospital in Baltimore, Maryland; Professor of Pediatric Orthopaedics, Johns Hopkins Medical Institution



Stefan Parent, M.D., Ph.D.
Orthopaedic Surgeon, Assistant
Professor of Surgery, University of
Montreal; Ste-Justine Pediatric Spinal
Deformity Academic Chair, Montreal,
Canada



John Asghar, M.D. Spine Surgeon at Department of Orthopaedics at Miami Children's Hospital in Miama, Florida



#### **HSG ASSOCIATE MEMBERS**

Associate Members, some of whom have served as Core Members, participate by contributing follow-up data on previously enrolled patients or by contributing patients to prospective studies.

#### Alvin Crawford, M.D.

Director Emeritus Crawford Spine Center, Cincinnati Children's Hospital Medical Center

#### Christopher Reilly, M.D.

Head and Assistant Professor, Division of Pediatric Orthopaedics at the British Columbia Children's Hospital; Director of Postgraduate Education in the University of British Columbia Department of Orthopaedics, Vancouver, British Columbia. Canada

#### Daniel J. Sucato, M.D.

Staff Orthopedist and Director of the Sarah M. And Charles E. Seay/Martha and Pat Beard Center for Excellence in Spine Research, Texas Scottish Rite Hospital for Children in Dallas, Texas; Professor, Department of Orthopaedic Surgery, University of Texas at Southwestern Medical Center

#### Dennis Wenger, M.D.

Rady Children's Hospital in San Diego, Clinical professor of Orthopaedic Surgery at the University of California, San Diego

#### Jean-Marc Mac-Thiong, M.D.

Assistant Professor, Department of surgery, University of Montreal, Orthopaedic surgeon and Researcher, Ste-Justine Hospital.

#### Jean Ouellet, M.D., FRCSC

Chief of Scoliosis & Spine Center, Montreal Children's Hospital in Montreal, Canada

#### Josh Pahys M.D.

Pediatric Spine Surgeon, Shriners Hospital for Children, Philadelphia

#### Lynn Letko, M.D.

Spinal surgeon at Klinikum Karlsbad Langensteinback, Karlsbad Germany

#### Mark Abel, M.D.

Lillian Pratt Distinguished Professor & Chair Department of Orthopaedic Surgery, Professor of Pediatrics, University of Virginia, Charlottesville, Virginia

#### Michael Kelly, M.D.

Assistant Professor, Orthopedic Surgery, Spine Surgery, Washington University School of Medicine

#### Michael O'Brien, M.D.

Medical Director of Research, Baylor Scoliosis Center, Plano, Texas

#### Munish Gupta, M.D.

Professor, Chief of Spine Service, Co-Director of the Spine Center, University of California, Davis Department of Orthopaedic Surgery, Sacramento, California

#### Peter G. Gabos, M.D.

Co-Director of the Division of Spine and Scoliosis Surgery, Nemours/Alfred I. DuPont Hospital for Children, Wilmington, Delaware; Assistant Clinical Professor of Orthopaedic Surgery, Jefferson Medical College, Philadelphia, Pennsylvania

#### Peter Sturm, M.D.

Alvin H. Crawford Chair Spine Surgery, Director Crawford Spine Center, Cincinnati Children's Hospital Medical Center, Ohio

#### Ronald A. Lehman, Jr., M.D.

Professor of Othropaedic and Neurological Surgery, Washington University School of Medicine

#### Stewart K. Tucker, M.D., FRCS

Consultant Spine Surgeon; Lead Clinical Spine Surgery, Great Ormond Street Hospital for Children; Royal National Orthopaedic Hospital, London, UK

#### Salil Upasani, M.D.

Rady Children's Hospital in San Diego, Clinical Assistant Professor

#### Tom Errico, M.D.

Professor; Chief Division Spine Surgery, Departments of Orthopaedic Surgeon and Neurosurgery

"Being a part of HSG has allowed me to be mentored and learn from the leaders in the field of scoliosis. From our discussions as a group we hear different perspectives on solving a particular problem, which taken together often results in a solution."

### PATIENT STORY



# FINANCIAL REPORT

### Fiscal Year 2013

### Revenue and Support

Research Grant	\$1,300,939
■ Contributions	\$189,328
■ Consulting	\$26,666
■ Database Leasing	\$22,121
Educational Income	\$19,043
■ Interest Revenue	\$11,766
■ Educational Income	\$19,043

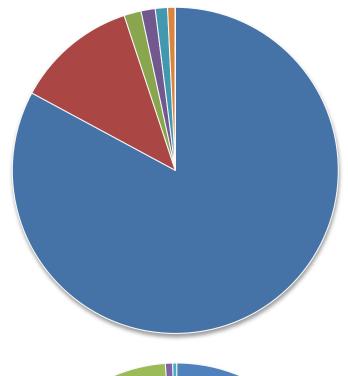
\$1,570,005

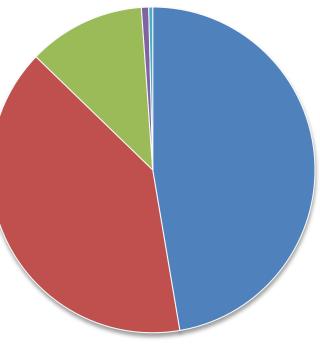
### Functional Expenses

Merchandise Comission

Research Site Reimbursements	\$575,611
Research Coordination	\$485,245
■ Management & General	\$141,554
■ Fundraising	\$8,769
■ Educational Material	\$4,798

\$1,215,978





### WITH APPRECIATION: 2013 DONORS

### **Appreciation for our Donors**

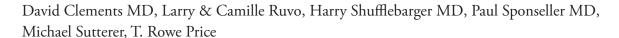
#### Platinum Level: \$20,000 and Adove

Lutz Biedermann, Jeffrey & Stacey Goldfarb, Peter & Cathy Newton

Gold Level: \$10,000 - \$19,999

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Silver Level: \$5,000 - \$9,999



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DePuy Synthes Spine, the
Orthopaedic Research and
Education Foundation, the
Scoliosis Research Society,
DePuy Synthes Spine Canada,
and EOS imaging.

Our mission to advance the care for patients with spinal deformities worldwide has been greatly enhanced by their support of our shared goals. We are very appreciative of their support, and we thank them all!

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www.settingscoliosisstraight.org

Contact the Harms Study Group via email at research@ssshsg.org

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# **HSG**HARMS STUDY GROUP

Pioneering Research in Spinal Deformities