



2016 ANNUAL REPORT



Supporting Discoveries in Spinal Deformities



GRATITUDE REPORT



Peter Newton, MD

President, Setting Scoliosis Straight Foundation

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

Every year, with your support, we use the discoveries of our research teams to make the lives of those affected by scoliosis better and better, and in 2016 this rang truer than ever. I am incredibly proud of what we have accomplished this past year, but I also realize that our job is far from done. Scoliosis continues to impact the lives of millions of children, teens, and adults around the world.

Setting Scoliosis Straight is committed to improving the decision making process by creating new evidence while educating surgeons and patients alike. Our patients are sharing the ways scoliosis affects their lives and telling us what issues are important to them that they want our research to solve. In light of this, we must thank our patients for focusing our efforts on their needs and for being willing research participants who will provide the answers to the questions and riddles of scoliosis which we all want solved! There are great strides that lie ahead, and with your support, we will enhance the lives of every patient and family affected by scoliosis.

Most Sincerely,

A handwritten signature in dark ink, appearing to read "Peter Newton".



Michelle Marks, PT, MA

Executive Director, Setting Scoliosis Straight Foundation

Dear Setting Scoliosis Straight and Harms Study Group Family,

This past year was filled with so many sources of inspiration for our organization. Inspiration came from our patients who were brave enough to share their journeys through spinal deformity so other patients could gain hope, lessen their fears, and not feel alone. Inspiration came from our patients' parents who anxiously waited for what felt like centuries in operating waiting rooms to finally hear from a surgeon that their child's spinal deformity surgery went well. Inspiration came from our Harms Study Group surgeon members, from

our Setting Scoliosis Straight board members, from our site coordinators, and from infrastructure team members who all united to work for one cause.

It is from this inspiration that strength and energy ignited to enable the success of our efforts in 2016. We are grateful for all of your support and inspiration. Your contributions keep the hope alive that the future holds only improvements in spinal deformity care. We promise to continue to use your inspiration to fuel the fire for even more success in 2017 and beyond.

Most Sincerely,

A handwritten signature in dark ink, appearing to read "Michelle Marks".

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Supporting Discoveries in Spinal Deformities



WHO WE ARE

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The Setting Scoliosis Straight Foundation is dedicated to advancing the treatment of scoliosis and spinal deformity in children via research and education.

CURRENT STRATEGIC PLAN GOALS

GOAL #1

Improve quality, safety, and uniform outcomes by being the leading global resource for institutions' standard of care and establish best practice guidelines for surgeons.

GOAL #2

Direct research on treatment solutions that improve quality of life for all patients with scoliosis from infancy through adulthood.

GOAL #3

Be the primary source of accurate, patient-centered information by providing unbiased, evidence-based research and education that answers the questions patients and their families have.

BOARD OF DIRECTORS



Peter Newton, MD
Chairman/ President



David Clements, MD
Vice President



Robert Stone, CPA
Treasurer



Michelle Marks, PT, MA
Secretary



Randal Betz, MD



Thomas Errico, MD



Stacey Goldfarb, Esq.



Howard Greenberg, CPA



Baron Lonner, MD



Alan Olsen



Amer Samdani, MD



Kevin Sayar, Esq.



Suken Shah, MD



Harry Shufflebarger, MD

BOARD MEMBER ACCOLADES



Harry Shufflebarger, MD, a founding member of the Harms Study Group (HSG) and board member of the Setting Scoliosis Straight Foundation (SSSF), was honored this year with a Lifetime Achievement Award at the Scoliosis Research Society's 51st Annual Meeting in Prague. The expanse of Dr. Shufflebarger's professional accomplishments drew international applause. We are grateful for Dr. Shufflebarger's numerous contributions to spinal deformity research and care, and we value his commitment not only to our group, but to scoliosis patients everywhere.



Peter Newton, MD, Harms Study Group President and Chairman of the Board of Setting Scoliosis Straight, was recently nominated to serve as the Vice President of the Scoliosis Research Society (SRS) in 2017 and President in 2018. Congratulations to Dr. Newton for this incredible achievement! We are confident that the SRS will fare well under his expertise, passion, and guidance.

WHAT DOES IT MEAN TO SUPPORT RESEARCH?

Supporting pediatric spine research goes beyond collecting and analyzing data. It goes beyond our infrastructure's never-ending battle to secure the funding needed to keep our research moving forward. It goes beyond Bunsen burners and white lab coats.

When you support pediatric spine research, you're supporting hundreds of thousands of kids who are diagnosed with scoliosis every year. You are supporting

parents as they turn to the internet to research their child's odds after a new diagnosis. You are providing children and their families comfort in knowing that, at any given moment, someone is working hard on their behalf. Supporting pediatric spine research means that you are improving lives today and advancing treatments for the children of tomorrow.



YOU CAN STOP THE DECLINE IN RESEARCH FUNDING THAT LOOMS ON THE HORIZON

Things change. As the economy ebbs and flows, so do our funding sources for pediatric spine research. Yet some things remain the same. Scoliosis still exists, and so does the need for better scoliosis treatments. With a decline in funding on the horizon, we turn to you, families whose lives have been impacted by scoliosis and supporters of our mission, to help us bridge the funding gap on the horizon. Your contributions are the

backbone of our research. You continuously drive the work of our foundation onward with support that is changing patients' lives for the better. We are indebted to the generosity that you have shown in the past and ask that you continue to stand with us and with our patients. Your engagement will enhance the lives of patients with scoliosis worldwide.

To learn more about enhanced giving opportunities, please see page 25.

"Medical science has proven time and again that when the resources are provided, great progress...can occur".

LEAH HUMES

Patient Story



I, like many others, was completely blindsided by my scoliosis diagnosis in 2012. I have always been a very active person and have competed on sports teams since the age of four. I started developing fairly severe back pain at the age of 15, but never thought too much of it. At that time, I was playing AAA soccer and basketball, in addition to representing my Montreal high school team in soccer, basketball, and flag football. Then I was admitted to a great independent boarding school.

During my two years at my school in Massachusetts, I continued to struggle with what became more severe back pain. It wasn't until the spring of 2012 that I finally went to the hospital for X-Rays, and I was devastated by the results. I had a 45 degree curvature and had to seriously consider surgery if I wanted to live comfortably and attempt to keep competing athletically. This meant that I would be out for my first year of college athletics. I was far from excited about this news. However, Dr. Parent and my dad reminded me to consider my options: take a year off for surgery or risk not being able to continue my athletic career at all due to severe pain.

The surgery alone frightened me. I couldn't help but worry that the surgery could go wrong, my athletic career could come to an end, or that I may not recover properly post-surgery. Well, all of those worries were for nothing!

Today, I am happy to say that I recovered tremendously and became a better and stronger athlete after my surgery. I no longer suffer from back pain. I was able to become an impact player on my college soccer team, and I had the honor of captaining my team during my senior year. I was also honored to receive the MVP award! I am healthy, happy, active, and stronger than ever. A big thank you to Dr. Parent and the Sainte-Justine Team in Montreal!

If you would like to share your story with our community, please contact us at info@ssshsg.org.

Visit our website at www.settingscoliosisstraight.org to read all of our patient stories.



WHAT WE DO



Founded in 1995, the Harms Study Group (HSG) is a worldwide cohort of surgeons who perform comprehensive, multi-center prospective research studies focused on adolescent spinal deformity.

Through comprehensive prospective research studies, questions regarding treatment

approach, techniques, and 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.

HSCG EXECUTIVE MEMBERS



Professor Jürgen Harms, MD
Chief of Spine Surgery at Klinik Heidelberg Germany; Founding Member of The Harms Study Group



Peter Newton, MD
Chief of the Division of Orthopedics and Scoliosis 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 President



Randal Betz, MD
Spine Surgeon, The Institute for Spine & Scoliosis, Lawrenceville, NJ; Professor of Orthopaedic Surgery at Temple University School of Medicine; Founding Member of The Harms Study Group; SSSF Board Member



Harry Shufflebarger, MD
Director of the Division of Pediatric Spinal Surgery, Nicklaus Children's Hospital, Miami, Florida; Member of The Harms Study Group; SSSF Board Member



Amer Samdani, MD
Chief of Surgery for Shriners Hospitals for Children, Philadelphia, Pennsylvania; Member of The Harms Study Group; SSSF Board Member



Michelle Marks, PT, MA
Research/Executive Director of the Setting Scoliosis Straight Foundation, San Diego, California; SSSF Board Secretary



David Clements, MD
Professor of Orthopaedic Surgery and Neurosurgery, Cooper Medical School of Rowan University, Glassboro, New Jersey; Founding Member of The Harms Study Group; SSSF Board Vice President

"Being a member of The Harms Study Group has been the single most important factor for my professional growth. Discussing issues that are important to improving patient care with leading surgeons has allowed me to become a better clinician, researcher, and educator which translates to improved care for the patients I treat."

- Amer Samdani, MD

HSG CORE MEMBERS

Membership in this group is by invitation of the Executive Committee.
Core members make significant contributions to the main studies of the group.



Firoz Miyanji, MD
British Columbia Children's Hospital
Vancouver, British Columbia, Canada

Hubert Labelle, MD
CHU Sainte-Justine
Montreal, Canada



Stefan Parent, MD, Ph.D.
CHU Sainte-Justine
Montreal, Canada



Randal Betz, MD
Institute for Spine & Scoliosis
Lawrenceville, New Jersey



David Clements, MD
Cooper Bone & Joint Institute
Candem, New Jersey



Peter Newton, MD
Rady Children's Hospital
San Diego, California



Burt Yaszay, MD
Rady Children's Hospital
San Diego, California



Amer Samdani, MD
Shriners Hospitals for Children
Philadelphia, Pennsylvania



Patrick Cahill, MD
Children's Hospital of Philadelphia
Philadelphia, Pennsylvania



Jack Flynn, MD
Children's Hospital of Philadelphia
Philadelphia, Pennsylvania





Daniel Hedequist, MD
Boston Children's Hospital
Boston, Massachusetts



Michael Glotzbecker, MD
Boston Children's Hospital
Boston, Massachusetts



Lawrence Lenke, MD
Columbia University
New York, New York



Baron Lonner, MD
Scoliosis & Spine Associates,
Mount Sinai Hospital
New York, New York



Suken Shah, MD
Nemours Alfred I. DuPont
Hospital for Children
Wilmington, Delaware



Paul Sponseller, MD
John Hopkins Hospital
Baltimore, Maryland



Harry Shufflebarger, MD
Nicklaus Children's Hospital
Miami, Florida



John Asghar, MD
Nicklaus Children's Hospital
Miami, Florida

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.

Mark Abel, MD
University of Virginia
Children's Center,
Charlottesville, Virginia

Tom Errico, MD
NYU Hospital for
Joint Diseases
New York, New York

Nicholas Fletcher, MD
Emory Children's Hospital
Atlanta, Georgia

Peter Gabos, MD
Nemours/Alfred I. DuPont
Hospital for Children
Wilmington, Delaware

Stephen George, MD
Nicklaus Children's Hospital
Miami, Florida

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St. Louis, Missouri

Steven Hwang, MD
Shriners Hospitals for Children
Philadelphia, Pennsylvania

Michael Kelly, MD
Washington University
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St. Louis, Missouri

Ronald Lehman Jr., MD
Columbia University
New York, New York

Jean-Marc Mac-Thiong, MD
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Montreal, Canada

Josh Pahys MD
Shriners Hospital for Children
Philadelphia, Pennsylvania

Christopher Reilly, MD
British Columbia
Children's Hospital
Vancouver, Canada

Ben Royce, MD
Columbia University
New York, New York

Peter Sturm, MD
Cincinnati Children's Hospital
Medical Center
Cincinnati, Ohio

Daniel Sucato, MD
Texas Scottish Rite
Hospital for Children
Dallas, Texas

Salil Upasani, MD
Rady Children's Hospital
San Diego, California

Michael Vitale, MD
Columbia University
New York, New York

EMERITUS MEMBERS

Alvin Crawford, MD
Cincinnati Children's Hospital
Cincinnati, Ohio

Dennis Wenger, MD
Rady Children's Hospital
San Diego, California

2016 POWER OVER SCOLIOSIS

PATIENT EDUCATION COURSE



Shriners Hospitals
for Children®



The Children's Hospital
of Philadelphia®

Nemours Alfred I. duPont
Hospital for Children

This year marked a huge milestone for Setting Scoliosis Straight in our pursuit to become the leading resource in evidence-based patient education. On May 14th, Shriners Hospitals for Children-Philadelphia graciously hosted our first patient education course entitled, Power Over Scoliosis. With over 120 attendees, 27 faculty, and 30 volunteers, this event raised the bar in scoliosis patient education. The day after the event, HSG surgeon member Jack Flynn, MD, shared these words:

Yesterday was an inspiring day for HSG surgeons who correct spine deformity and counsel kids through non-op care. The patient panels, the family Q&A, and the patient testimonials drove home the

value of the work we do. These powerful patient stories, and their unanswered questions, inspire us. We will do better now in pursuing answers to the research questions that interest families, not just the things that interest surgeons.

We want to offer special thanks to our institutional support: Shriners Hospitals for Children-Philadelphia, Children's Hospital of Philadelphia, and Nemours Alfred I. duPont Pediatrics for making this event possible! We also want to thank all program attendees, patient panelists, faculty, sponsors, and volunteers for the collaborative efforts that went into making this event such a success!



Courtney Rone

Miss Teen New Jersey International 2016 & SSSF Scoliosis Ambassador

Courtney Rone has a scar that spans from the middle of her shoulder blades all the way down her lower back. Today the scar resembles a faint white line and serves as a daily reminder of her inner strength and how far she's come.

"Courtney is a great example of what can be achieved with scoliosis surgery at a place like Children's Hospital of Philadelphia. We perform the highest quality procedures for young people with spinal deformities and always consider a patient's individual lifestyle before making treatment decisions. While our priority is to safely correct and stabilize the spinal curvature, we always try to preserve the patient's flexibility if possible. Our goal is for patients to be able to return fully to the sports and activities that they love. And when you have the commitment to physical therapy that we saw with Courtney, the end result can be absolutely incredible."

- Wudbhav Sankar, MD
Children's Hospital of Philadelphia

2016 STARSTRUCK GALA

At the StarStruck Gala, six former Adolescent Idiopathic Scoliosis patients were awarded for their shining accomplishments as ambassadors for scoliosis.

Haley Gelberg, Student

“You’re braver than you believe, stronger than you seem,
and smarter than you think.”



Lindsay Gordon, Student

“For anyone who ever feels alone in their journey or just wants to give up,
I want you to know that if you keep your head held high, you can achieve
your goals and reach the finish line before you know it.”





Co-Chairwomen Robin Gordon and Jenn Padilla

Jarrood Padilla, Student

"All I wanted to be was just a regular kid who ran track, played video games, and hung out with my friends. With some patience on my part and the support from my family, friends, and Dr. Pahys, I realized that I am a regular kid and I can still do all of these things in spite of scoliosis."



Caleigh Stednitz, Artist

"While the entire process of treating my scoliosis was difficult, I have no regrets about having surgery. I find solace in my experience. It allowed me to combine something I had to do with something I love to do. It presented me with the chance to cope with scoliosis through art."

Courtney Burns, Student

"We all have the ability to shape our experiences to make the world a better place."

(Courtney is spearheading an international project that recycles back braces from patients in the United States to send to children in need around the world.)



Kelly Andersen, News Anchor for KVAL

"Scoliosis doesn't just debilitate your health, it debilitates your self-esteem and your sense of self-worth. When you can't love the body that you're in, it's hard to love the person that exists inside of it. Shriners Hospitals for Children-Philadelphia has given me the invaluable gift to love myself and every twist and turn that was handed to me."

2016 SCIENTIFIC PRESENTATIONS

Year	Podium Presentations*	Poster Presentations*	Manuscripts Published^
2011	27	34	14
2012	23	27	12
2013	22	16	14
2014	29	16	13
2015	32	13	15
2016	37	12	15

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



SRS: 17 Podiums, 6 Posters
IMAST: 3 Podiums



7 Podiums, 5 Posters



8 Podiums, 1 Poster



1 Podium



1 Podium

2016 SCIENTIFIC PUBLICATIONS

1. Samdani AF et al. . Major Perioperative Complications After Spine Surgery in Patients with Cerebral Palsy: Assessment of Risk Factors. *Eur Spine J.* (2016) 25:795-800.
2. Schoenleber SJ, et al. Are S1 Screws a Useful Adjunct to Iliac Screws in Long Fusions to the Sacrum in Cerebral Palsy? *Spine (Phila Pa 1976)* 41(2):139-45, Jan 2016.
3. Pawelek JB, et al. Case-Matched Comparison of Spinal Fusion Versus Growing Rods for Progressive Idiopathic Scoliosis in Skeletally Immature Patients. *Spine (Phila Pa 1976)*. 2016 Feb;41(3):234-8. doi: 10.1097/BRS.0000000000001198
4. Souder C, et al. Factors in Surgical Decision Making for Thoracolumbar/Lumbar AIS: It's About More Than Just the Curve Magnitude. *J Pediatr Orthop.* 2016 Mar 3. [Epub ahead of print]
5. Amir D et al. Does Leveling the Upper Thoracic Spine Have Any Impact on Postoperative Clinical Shoulder Balance in Lenke 1 and 2 Patients? *Spine (Phila Pa 1976)*. 2016 Feb 8. [Epub ahead of print]
6. Auerbach JD, et al. Delayed Postoperative Neurologic Deficits in Spinal Deformity Surgery. *Spine (Phila Pa 1976)*. 2016 Feb;41(3):E131-8. doi: 10.1097/BRS.0000000000001194.
7. Jain A, Sponseller PD et al.. Incidence of and Risk Factors for Loss of One Blood Volume During Spinal Fusion Surgery in Patients with Cerebral Palsy. *J Pediatr Orthop.* 2016; in press
8. Yaszay B, et al. The Effects of the Three-Dimensional Deformity of Adolescent Idiopathic Scoliosis on Pulmonary Function. *Eur Spine J.* 2016 Aug 11. [Epub ahead of print]
9. Murphy JS, et al. Predictors of Distal Adding-On in Thoracic Major Curves with AR Lumbar Modifiers. *Spine (Phila Pa 1976)*. 2016 Jul 7. [Epub ahead of print]
10. Yaszay B, et al. Performing a Definitive Fusion in Juvenile CP Patients is a Good Surgical Option. *J Pediatr Orthop.* 2016 Jun 2. [Epub ahead of print]
11. Samdani AF, et al. Reversible Intraoperative Neurophysiologic Monitoring Alerts in Patients Undergoing Arthrodesis for Adolescent Idiopathic Scoliosis: What Are the Outcomes of Surgery? *J Bone Joint Surg Am.* 2016 Sep 7;98(17):1478-83. doi: 10.2106/JBJS.15.01379.
12. Wang W. et al. Biomechanics of High-Grade Spondylolisthesis with and without Reduction. *Med Biol Eng Comput.* 2016 Apr; 54(4): 619-628. Doi: 10.1007/s11517-015-1353-0.
13. Mac-Thiong JM et al. Posterior Convex Release and Interbody Fusion for Thoracic Scoliosis: Technical Note. *Journal of Neurosurgery Spine.* 2016 Sep; 25(3): 357-65. Doi: 10.3171/2016.2SPINE15557.
14. Jain A., et al. Subclassification of GMFCS Level-5 Cerebral Palsy as a Predictor of Complications and Health-Related Quality of Life After Spinal Arthrodesis. *J Bone Joint Surg Am.* 2016 Nov; 98(21): 1821-1828. Doi: 10.2106 / JBJS.15.01359
15. Schoenleber SJ et al. The Assessment and Treatment of High-Grade Lumbosacral Spondylolisthesis and Spondyloptosis in Children and Young Adults. *JBJS Rev.* 2015 Dec 15; 3(12). pii: 01874474-201512000-00006. doi: 10.2106/JBJS.RVW.O.00015. No abstract available.

CEREBRAL PALSY STUDY

Prospective Database Registry Study

Primary investigator, **Paul Sponseller, MD**, of Johns Hopkins Hospital in Baltimore, Maryland, is committed to leading this research effort which answer important clinical questions for this medically fragile patient population.

A quick look at

2016 CP research efforts include:

- Are Severely Underweight Patients with Cerebral Palsy at a Higher Risk for Complications and Poorer Outcomes Following Posterior Spinal Fusion for Scoliosis?
- Analysis of Patients with Cerebral Palsy Requiring Reoperation After Spinal Fusion: Associated Risk Factors and Impact on Quality of Life.
- What Are the Indications to Fuse Short of the Pelvis in CP Scoliosis?
- Assessing the Risk/Benefit Ratio of Scoliosis Surgery in CP: Is Surgery Worth It?

Although questions remain for this study effort, we look forward to uncovering critical information to not only improve, but restore, quality of life for children living with cerebral palsy and scoliosis in 2017 and beyond. We are grateful for our study participants, our research sites and sponsor support from **DePuy Synthes Spine** and **K2M**!

Our research sites
have been enrolling
in this prospective study
since 2008. Patients are
evaluated for five years
of follow-up.

122
non-operative
patients

482
operative patients



CP patient Keith Johnson with his doctor Stephen George

“The Harms Study Group allows me to collaborate with innovative and passionate surgeons, who are sincerely dedicated to the pursuit of excellence in pediatric spinal deformity care.”

- Stephen George, MD

ADOLESCENT IDIOPATHIC SCOLIOSIS STUDY

(AIS) Database Registry Study

The longstanding commitment and support from our primary sponsor for this research study, **DePuy Synthes Spine**, has enabled our study group to establish and maintain the largest prospective series of Adolescent Idiopathic Scoliosis patient outcomes in existence. We are extremely grateful for their support.

Primary investigator, **Peter Newton, MD**,

remains the driving force behind this study effort, as he works with all Harms Study Group surgeon members to ensure important clinical questions are being answered with this robust data set.

A total of 40 research abstracts were generated and submitted for presentation this year from our AIS outcomes study. Many discoveries were presented at scientific meetings across the globe.

A few of the research endeavors

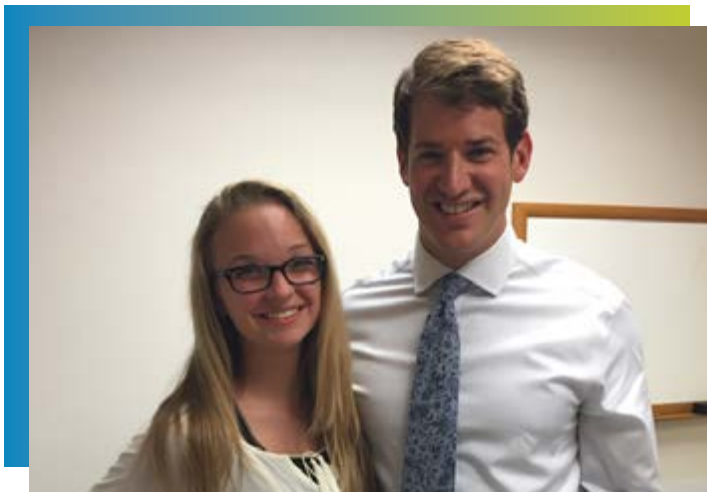
associated with this study in 2016 include:

- Surgery for the Adolescent Idiopathic Scoliosis Patients After Skeletal Maturity: Now or Later?
- A Critical Assessment of ≥ 10 -Year Follow-Up of Spinal Fusions for Adolescent Idiopathic Scoliosis: Outcome Improvement Opportunities Remain.
- Major Complications at Two Years After Surgery Impacts SRS Questionnaire Scores for Adolescent Idiopathic Scoliosis Patients.
- Patient-Centered Research: Do Clinicians and Patients Agree on Scoliosis Research Priorities?

483
non-operative
patients

Research sites
began enrollment of
patients with AIS in 1995
with a goal of tracking
patients for 25 years after
their surgery.

4843
operative patients



AIS patient Caroline Tracy with her doctor Nicholas Fletcher

SCOLIOSIS TREATMENT BEST PRACTICE GUIDELINES

The Harms Study Group held two meetings in 2016. Three Delphi sessions, in which experts anonymously answered future treatment questions and discussed results, focused on decreasing length of hospitalization following spinal fusion surgery in children with AIS through improved treatment.

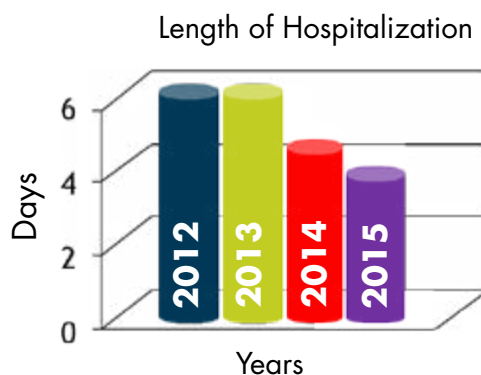
This Delphi process resulted in the development of a consensus-based Best Practice Guideline (BPG) for post-operative care following posterior spinal fusion for AIS. Twenty-six surgeons participated in this effort. A summary of this BPG has been shared with the members of the Scoliosis Research Society and the Pediatric Orthopedic Society of North America.

Following the development of our preliminary BPG for postoperative care (in 2013), we saw a reduction in length of hospitalization stay in all sites that implemented the BPG. The average reduction in hospital stay across all participating centers was at least one day.

The reduction in length of hospital stay continued to shorten in sites who adopted the BPG as a new standard of care.



Our robust, multi-center database allowed us to identify significant variability in post-operative care following spinal fusion for AIS. Preliminary data provided evidence for the development of a consensus-based best practice guideline which improves care for AIS patients who undergo spinal fusions. We have shared this information with the world, and we vigilantly look for ways to globally improve care for patients with spinal deformities.



"We took the individual variability of the research sites and harnessed the collective wisdom of the group and the open-mindedness of our surgeons to initiate change. Using the Delphi process we validated this treatment pathway and made care better. This collaboration was one of the most impactful improvements in spinal deformity care that I have been involved in."

- Suken Shah, MD

LOOKING TO THE FUTURE

Evaluating the Spine in 3D

Scoliosis is a complex spinal deformity with vertebral deviations that are three-dimensional (3D). Through the generous support of EOS Imaging, our AIS outcomes database is converting from 2D to 3D reconstructions for our radiographic analyses. The EOS Imaging system is a new, low-dose, orthopedic imaging device based on Nobel prize winning X-ray detection technology with special software for 3D surface reconstruction capabilities. Participating research sites have fully integrated the EOS Imaging System into their medical imaging processes.



The benefit to the patient is a significantly lower radiation dose: 2-3x less than a general computed radiography X-ray and 20x less than basic computed tomography (CT) scans. The 3D reconstructions obtained from this imaging system have opened valuable new areas of research in the assessment and treatment of spinal deformities:

Which AIS curves will progress to need surgery?

Which patients will benefit most from a shorter fusion?

Where does correction occur, and where does curve progression occur over time?

Long-Term Outcomes in Adolescent Idiopathic Scoliosis

Long-term follow-up data of more than 10 years is sparse in surgically treated patients with Adolescent Idiopathic Scoliosis (AIS). Thus, there is a strong need for prospectively collected long-term follow-up data in these patients, particularly those with modern instrumentation. Patients want to know what changes to expect with time, and surgeons need to know what to tell their patients. Surgeons need to know of radiographic changes, spinal balance changes, and any complications that may happen at the 10, 20, and 25 year post-operative time marks. Patients need to report these changes.

Our research group is the longest in existence and has been prospectively enrolling patients since 1995. We are the group that can successfully collect this data. There are currently 650 patients who have been prospectively enrolled and followed post-operatively at the two year and five year time points, and these patients are now due back for their 10+ year follow-up visits. We don't want to

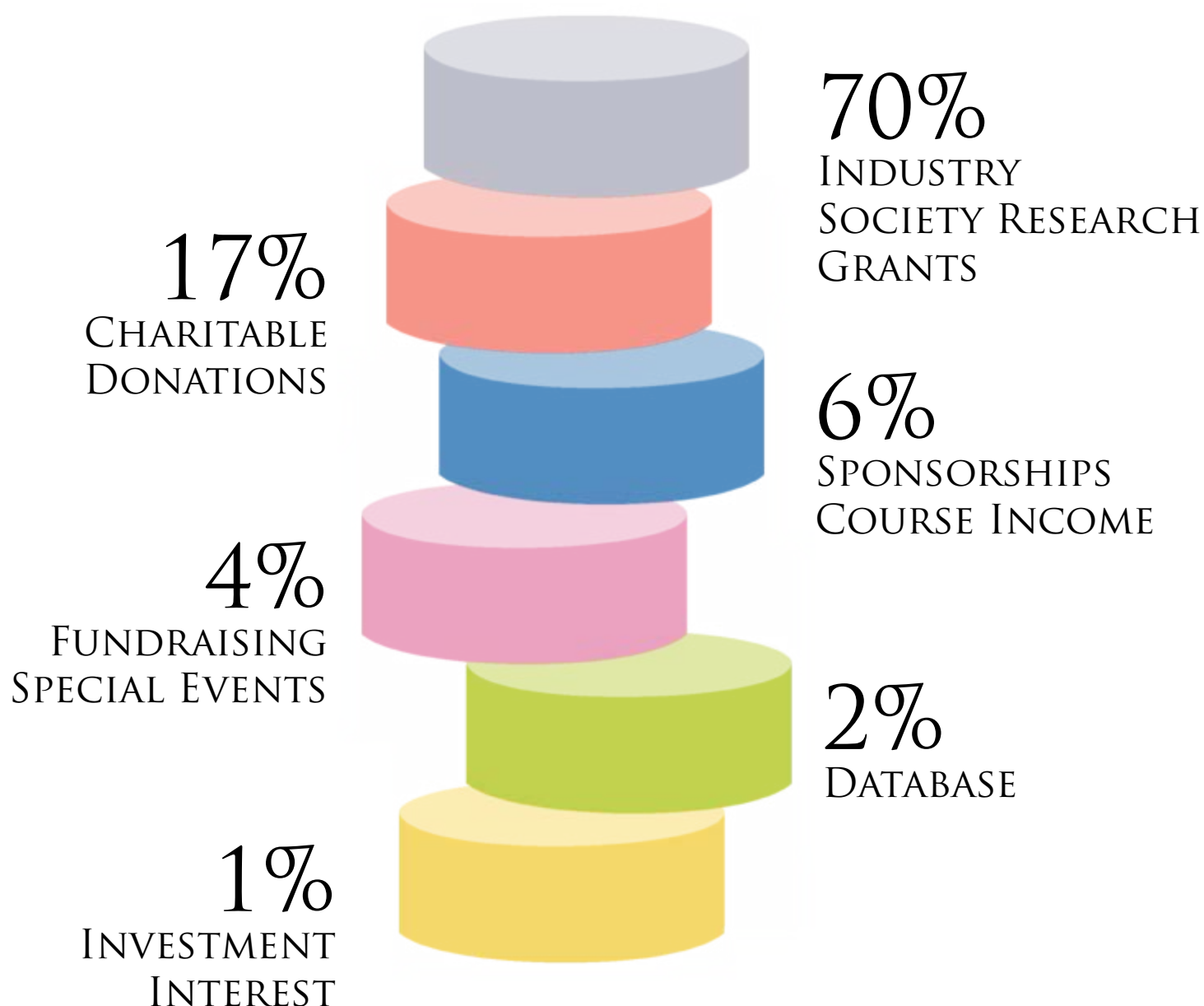
miss the monumental opportunity to obtain long-term follow-up data from this existing patient population, and we are hopeful we can secure the funding sorely needed to support this research.

**Interested in
supporting these efforts?**

Please visit:
www.settingscoliosisstraight.org!

FINANCIAL REPORT

Revenue & Support



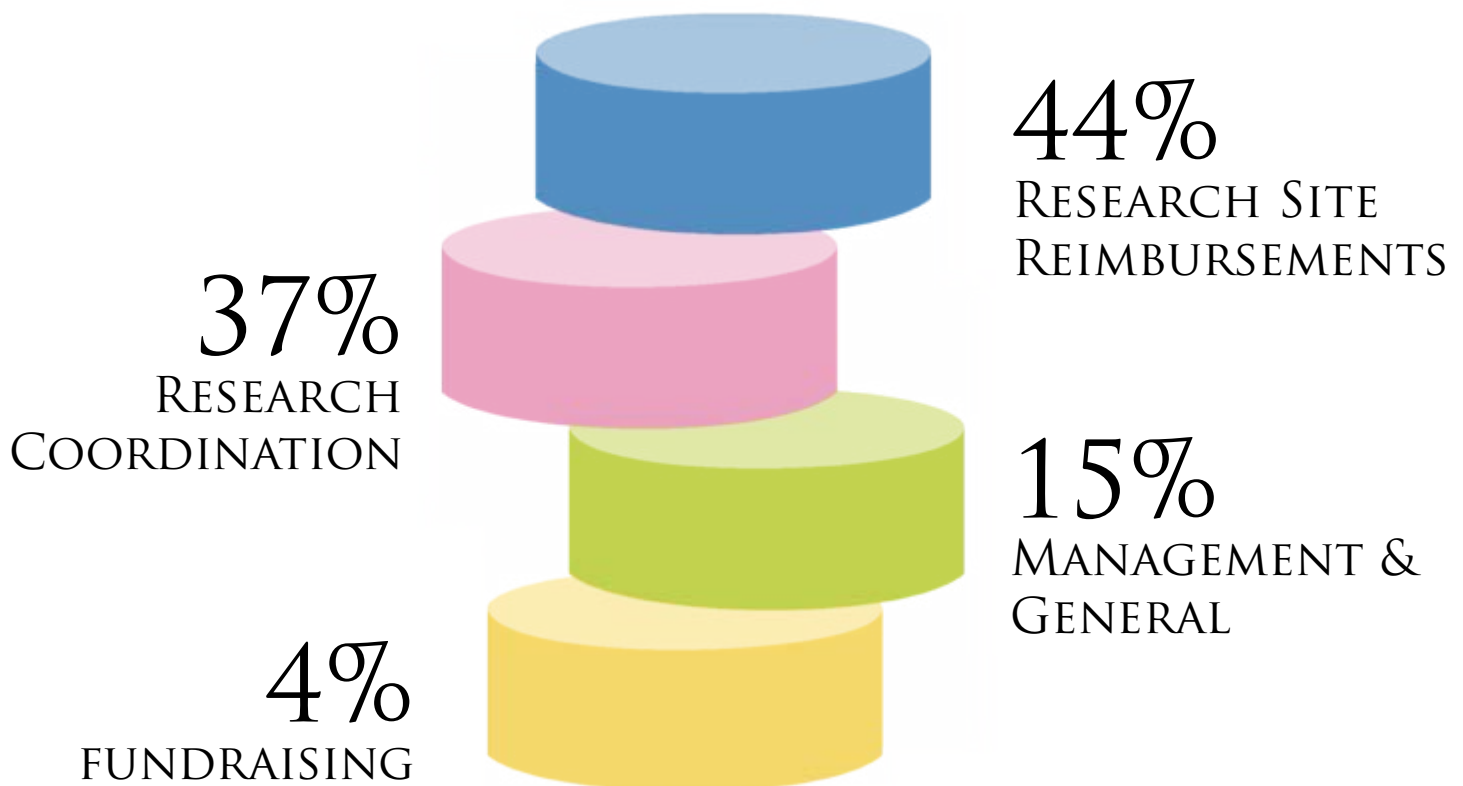
FISCAL YEAR 2016

Functional Expenses

82 **EIGHTY-TWO PERCENT** OF EVERY DOLLAR WE RECEIVE GOES DIRECTLY TO **OUR MISSION** AND **OUR COMMITMENT**.

Our mission: to advance the care of patients with spinal deformities.

Our commitment: to provide education on spinal deformity treatments to patients, patient families, surgeons, and healthcare providers.



2016 GIVING

Our Organization's growth and success is made possible due to the continued support of our 2016 Program Contributions and Sponsorships from our research colleagues. We thank you!

Industry Research Study Sponsors, Special Event Sponsors, & Donors:

Diamond: \$1,000,000+

DePuy Spine, Inc.
Johnson & Johnson Medical Products

Platinum: \$500,000 - \$999,999

Gold: \$250,000 - \$499,999

K2M, Inc.

Silver: \$100,000 - \$249,999

Bronze: \$50,000 - \$99,999

EOS Imaging Inc.
Zimmer Biomet
CHU Sainte-Justine

Copper: \$20,000 - \$49,999

Titanium: \$10,000 - \$19,999

Steel: \$5,000 - \$9,999

Ellipse Technologies Inc.
Globus Medical
Lawall Prosthetic & Orthotic Services
Medtronic Spinal
NuVasive
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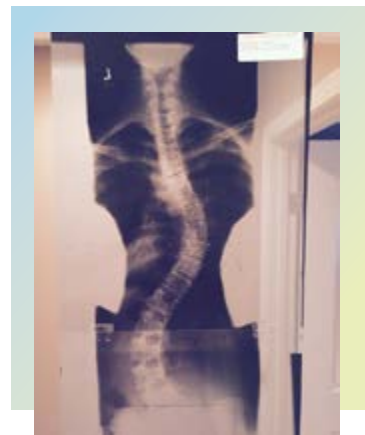
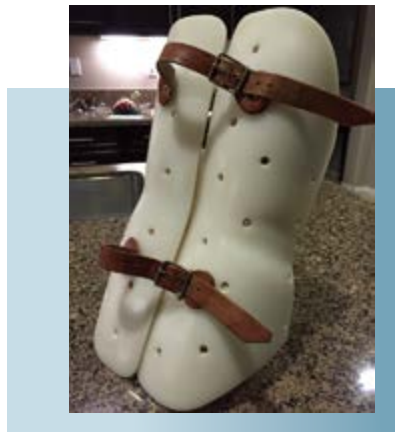
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Meet LINDSAY ELLINGSON

*SSS Celebrity
Spokesperson*



Lindsay's involvement marks a pivotal turning point for Setting Scoliosis Straight. As the organization's first spokesperson, Lindsay wants to use her celebrity platform to bring attention to a cause she feels remains important and severely underrepresented.



Why Lindsay's Big Story Makes Her a Great Spokeswoman!

Lindsay is probably best known for her incredible modeling career. She's walked catwalks all over the world, opened for big fashion designers, and had her warm girl-next-door face on major billboards all across the country. Despite her grandiose career, Lindsay is as real and genuine as it gets.

As a little girl, Lindsay enjoyed gymnastics more than anything else. Then one day in gymnastics class, her coach noticed something odd about Lindsay's back and advised her mom to take her to the doctor. This is when Lindsay learned she had scoliosis and was going to have to wear a brace. The hits kept coming. The next thing

she learned was that she would have to quit what she loved most—gymnastics. Distraught, she pressed on but remained hopeful.

Like other young girls with scoliosis, Lindsay struggled as she tried to feel “normal” strapped inside a thick plastic brace all day. Despite Lindsay's best efforts to diligently wear her brace, her curves progressed, and she was told she would need surgery. Lindsay recounts that time in her life as being especially challenging, but with help and support, Lindsay was able to gather the strength needed to come out of surgery with a new outlook on life. She felt invincible! She felt a little more complete. She felt a little more like herself.

Today, Lindsay hopes to inspire others to dream big and never give up hope.

“I hope to really build this platform to bring more people together because it's so important to feel like part of a community, to be able to share your story...to just relate to each other, to feel inspired, and ultimately to give each other hope.”

- Lindsay Ellingson



To read Lindsay's complete story, visit our website at www.settingscoliosisstraight.org.



Our goal is to talk about giving in an open way and create an atmosphere that draws more people to understand the value and importance of supporting pediatric spine research. Enhance your involvement in the upcoming year by exploring a new channel of giving highlighted in the Happy-Giver Model below. Your contributions are the lifeblood of our research, continuously driving the mission of this organization forward.

THE HAPPY-GIVER MODEL

MONTHLY GIVING

Amplify your gift by joining our Monthly Givers Club! Monthly giving is an easy, stress-free, and effective way to make scoliosis awareness a part of your life. Monthly gifts typically range from \$5-\$100 and can start, stop, and/or be paused anytime.

THE GIVING PLEDGE

For loyal supporters of the organization, multi-year pledges help address our most pressing concerns by staying future-focused. Pledges provide critical ongoing support while providing the stability needed to reach more, help more, and do more together.

PLANNED GIVING

For those whose commitment to pediatric spine research and SSS is deeply rooted, we urge you to consider planned giving. As a Planned Giver, your contribution will make a profound difference in the lives of children for generations to come. Your service and care for the cause will be felt indefinitely.

Thank you for your help. Thank you for believing in us. But most of all, thank you for trusting in research and the integral role it plays in safeguarding the lives of children living with spinal deformities worldwide.



At Setting Scoliosis Straight, families remain at the core of everything we do and everything we stand for because scoliosis doesn't just affect one individual, it affects the health, function, and well-being of the entire family.

For this reason, Setting Scoliosis Straight formed the Foundation Family—a group for members of the community, grateful families, and caring friends who want to come together and commit to raising awareness for a cause that has been severely underrepresented. What started as a small group of eager volunteers has transformed into network of over 400 Foundation Family members!

We want to offer a huge and heartfelt **THANK YOU** to our Foundation Family. For your unwavering support, energy, and enthusiasm throughout the years, we thank you. You have been essential to the health and well-being of our organization.

WE COULDN'T DO IT WITHOUT YOU.

To join Setting Scoliosis Straight's Foundation Family, contact:

Chloe Petcharaporn at cpetch@ssshsg.org or call

SSS Headquarters at (619) 810-1430.

You can also fill out a quick Foundation Family form by going to:

<https://www.surveymonkey.com/r/63LQ9C7>

INFRASTRUCTURE



Michelle Marks
Executive/Research Director
Born in: Baton Rouge, LA

Michelle has been with SSS since 1998.



Tracey Bastrom
Statistical Analysis
Born in: Mineola, NY

Tracey has been with SSS since 2000.



Maty Petcharaporn
Research/Database Manager
Born in: Chicago, IL

Maty has been working for SSS since 1999.



Noreen Gaynor
Administrative Assistant
Born in: Jamaica, NY

Noreen has been with SSS since 2014.



Harvey Ly
**Development/Web Master/
Research Assistant**
Born in: San Diego, CA

Harvey joined the SSS Team in 2010.



Chloe Petcharaporn
Development Manager
Born in: San Diego, CA

Chloe has been with SSS since 2015.



Amy Bartley
Development/QA Manager
Born in: Merced, CA

Amy joined the SSS Team in 2011.



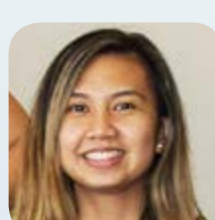
Kerry Betancourt
Research Assistant
Born in: Annapolis, MD

Kerry has been with SSS since 2016.



Jon Marie Basel
Contracts and Finance Manager
Born in: Tucson, AZ

Jon Marie joined the SSS Team in 2011.



Mary Dalupang
Research Assistant
Born in: Philippines, Manila

Mary has been with SSS since 2016.

2017 SPECIAL EVENTS



Special Honoree:
Harry L. Shufflebarger, MD
Director of the Pediatric Spinal Surgery Division
Nicklaus Children's Hospital

POWER OVER SCOLIOSIS

This one-of-a-kind educational experience covers the nuts and bolts of scoliosis treatment while empowering scoliosis patients in their care, treatment and success. Join families just like yours for this FREE, COMPREHENSIVE, and FUN learning opportunity!

Date: Saturday, June 3, 2017

Time: 9:30 a.m. to 3:30 p.m.

Location: Nicklaus Children's Hospital, Coral Gables

Cost: FREE

Give BACKS Hope

Following Power Over Scoliosis, join us at The Biltmore for Give Backs Hope!, a special event aimed to raise awareness and strengthen the community's support for pediatric spine research. In addition, Dr. Harry Shufflebarger, of Nicklaus Children's Hospital, will be honored for his lifetime commitment and care to his patients and in advancing pediatric spine research.

Date: Saturday, June 3, 2017

Time: 4:30 p.m. to 6:30 p.m.

Location: The Biltmore, Coral Gables

Cost: \$25 for Adults, FREE for Children

register: www.settingscoliosisstraight.org



Setting Scoliosis Straight

2535 Camino Del Rio South, Suite 325
San Diego, CA 92108

T 619.810.1430 F 619.810.1433

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

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