



2015 ANNUAL REPORT
CELEBRATING
20 YEARS
OF EXCELLENCE

 setting
SCOLIOSIS
straight

Supporting Discoveries in Spinal Deformities

**HSG**
HARMS STUDY GROUP
Pioneering Research in Spinal Deformities

PRESIDENT'S REPORT



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

We want to thank you for all of your efforts in helping us make 2015 such a productive and successful year. We celebrated the 20th anniversary of the study group in January with a spectacular gala held in Las Vegas. Our patients and supporters joined us for a wonderful evening as we looked back over what has been accomplished in the past two decades.

In the pages that follow, you will find highlights from this past year that emphasize the research and education effort that continue to increase the understanding and treatment of scoliosis. I want to thank and acknowledge all of our patients who have contributed their outcome data into our registry; without your willingness to participate in our research, we wouldn't be able to continue advancing the bank of knowledge for those who will be diagnosed with scoliosis in the future. Thank you!

Our research teams continue to apply increasingly sophisticated techniques as we study the complex curvatures of the spine and how they develop in adolescent patients. Three-dimensional imaging methods are changing what we know about spinal deformities, and just as we know that each patient is different and unique, we are now designing treatments to be patient specific. As the healthcare industry has shifted its focus to *quality* and *value* of care, the Harms Study Group has increased its focus on these areas as well, and we have led improvements on several fronts. We established a best practices guideline to facilitate postoperative scoliosis surgery recovery. This has resulted in hundreds of reduced days of hospitalizations and substantial health care dollar savings. Patients are going home and recovering faster than ever. We continue to use our large data set to drive quality improvement and give surgeons report cards on their performance.

The education portion of our mission remains a prominent focus in our work. We have a textbook focusing on Neuromuscular Scoliosis that will serve as another volume in the series to accompany our prior textbook on Idiopathic Scoliosis. The long-term surgical and non-surgical outcomes in scoliosis treatments remain a priority of the Harms Study Group.

While I am incredibly proud of what we have accomplished this past year, I also realize that our job is never done. We have set our sights higher with aggressive goals for growth and discovery. There are great strides to be made ahead, and with your support, we will share even more successes in 2016.

Most Sincerely,

A handwritten signature in black ink, which appears to read "Peter Newton".

Peter Newton, MD

President, Setting Scoliosis Straight Foundation

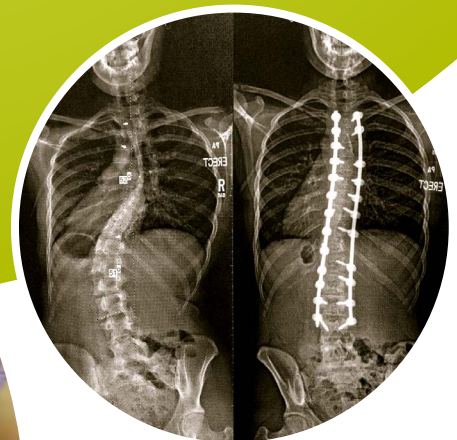
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20TH ANNIVERSARY

This event was sponsored by:



SPINE

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Lutz Biedermann

Medtronic



Tables sponsored by:

Randal Betz, MD
Tamara & David Clements
Alvin Crawford, MD
Thomas Errico, MD
BCCH Spine Team
John Hopkins University
Lawrence Lenke, MD

Alan Olsen
Michael Kelly, MD
Baron Lonner, MD
Peter Newton, MD
Harry Shufflebarger, MD
SpineGuard, Inc
Stefan Parent, MD PhD

In-kind donations:

Larry Ruvo

On January 24, 2015, we celebrated twenty years of cutting edge spinal deformity research. We want to thank everyone for their generous support over the past twenty years, and we look forward to leading patients, families, and healthcare providers through another twenty years of progress.

We hope you will join us in Philadelphia this year for our “Power Over Scoliosis” patient education course and our “StarStruck” celebratory patient gala on May 14, 2016! The four patients who spoke at our 2015 gala made it a magically memorable evening!

EVE MOLL

“On My Way” is Eve Moll’s response to scoliosis.

“Thank you for your countless hours of effort and research, for your immeasurable dedication to patients like me, and for your heroic efforts of developing and improving scoliosis treatment. Thank you for building my bridge.”

Eve painted this amazing piece of art for our silent auction and created beautiful cards for all in attendance.





KATIE LYONS

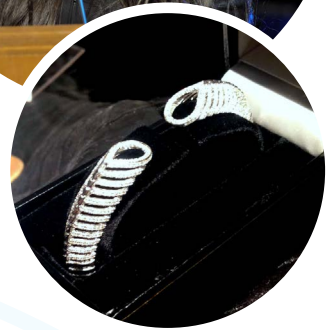
The books Katie read about spine surgery were full of doom. They promised a life of limitations. Then she met a doctor who said, “I can get you back to skiing.” That is when her life improved.

NATALIE LEWIS

Without surgery, Natalie’s organs would have collapsed, and she would have died. Today, as she’s working on starting her own family, she wants people with scoliosis to know that they are bent, not broken.



Natalie designed & donated a silent auction item - a diamond bracelet designed like a spine!



EMMA SAYAR

Emma’s back isn’t full of rods and screws. It’s tethered, and the tether in her back tie her to the future of scoliosis.

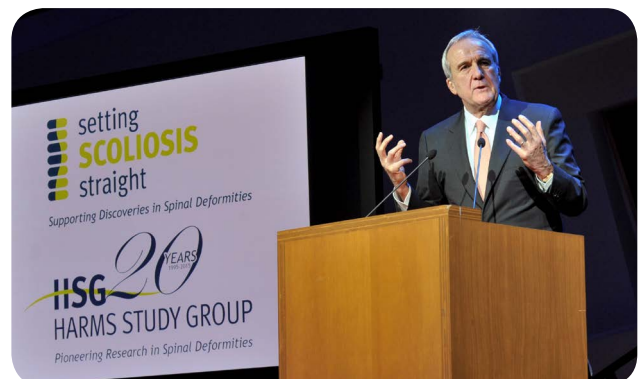
LARRY RUVO: The Spirit of Inspiration

While much of Larry Ruvo’s philanthropy is tied to Alzheimer’s, via Keep Memory Alive & the Lou Ruvo Brain Institute, scoliosis has also won a spot in Larry Ruvo’s heart. His daughter, Brianna, had corrective surgery for her scoliosis that was performed by Dr. Peter Newton in San Diego. This initial introduction eventually led to a working relationship between Dr. Newton and Larry Ruvo, which in turn led to Larry Ruvo stepping in to help Setting Scoliosis Straight turn twenty years old.

Larry Ruvo offered the Lou Ruvo Brain Institute’s amazing Keep Memory Alive Center for our very first fundraising gala. He staffed our gala and provided free drinks to all of our guests. Mr. Ruvo’s inspirational comments helped make the very first

SSS gala an evening that was truly unforgettable.

We are so indebted to his kindness and guidance. We want to thank Mr. Ruvo for continuing to inspire us!



The logo consists of five horizontal bars of varying lengths, stacked vertically. Each bar is divided into two sections: a blue section on the left and a yellow section on the right.

setting SCOLIOSIS straight

Supporting Discoveries in Spinal Deformities

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

Advancements in scoliosis treatment take time, resources, and dedication. In 2014, SSS staff devoted their time to ensuring that 2015's fundraising efforts would go above and beyond all previous fundraising drives. In 2015, Setting Scoliosis Straight hosted a live gala in honor of *twenty years* of the Harms Study Group.

Surgeons, patients, and scoliosis supporters gathered to celebrate the path scoliosis patients have walked and the future trails scoliosis treatments will take. Twenty years from now, we plan to look back at 2015 as the year that Setting Scoliosis Straight's fundraising efforts took us to new heights that were previously unimagined.

28 PATIENT STORIES!

Each patient who has spinal surgery has a unique story to tell. Setting Scoliosis Straight has 28 inspirational stories from patients who have had spinal surgery and now wish to share their success with others.



Our patient stories come from many different parts of the country.



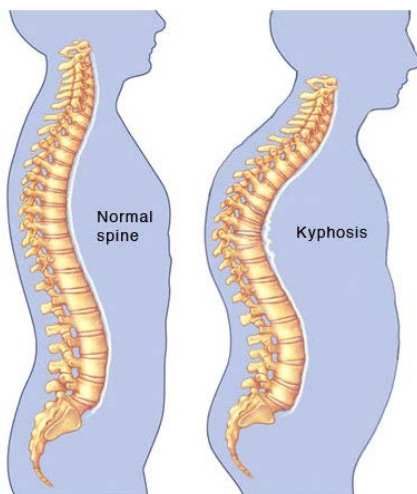
From left to right:
Don Holmes, Mark Feger, Isabel Holmes,
Penny Holmes, and Dr. Mark Abel.

MEET ISABEL & DR. ABEL FROM VIRGINIA

Isabel was born prematurely at twenty-nine weeks and was later diagnosis with Cerebral Palsy. As Isabel grew her spine curvature did too, and the severity of her curves started causing her a lot of discomfort and pain. Isabel had multiple surgeries to fix both kyphotic round back curves and lordotic sway back curves. Isabel's surgeries were a success! She has been under the care of Dr. Mark Abel since 2001.

Because of her surgeries:

- Isabel feels less pain.
- Her sleep has improved.
- She takes less medication.
- She can face forward/see who she is talking to.
- She has increased lung capacity.
- Her speech has improved.
- She is able to talk more with her parents!



“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.”

-- Penny Holmes

GRATEFUL PATIENTS

There are so many patients whose lives are greatly transformed after spinal surgery. It is not uncommon for patients to feel as if they have been given a gift, and similarly, it is not uncommon for these patients to want to give something back. Setting Scoliosis Straight currently has **six** amazing patients who help support our mission by raising scoliosis awareness and furthering the scope of our research. We hope to grow our grateful patient program and allow more patients to give back.



Our Grateful Patients Have Your Back!

What does it take to be a grateful patient? Our grateful patients are equal parts gratitude and action!

These patients have been challenged by life, and they have risen to the occasion and met their challenges head-on. During the hardest parts of their scoliosis journeys, they received help—from doctors, nurses, family, and friends—and now they want to give back.

Our grateful patients have a message for other patients with scoliosis:

***You're not alone!
We've got your back!***



Lindsay Gordon Wants to See You Strut!

In 2011, I was diagnosed with adolescent idiopathic scoliosis. Scoliosis led me down a curvy path with many ups and downs, but Dr. Jack Flynn, at Children's Hospital of Philadelphia, constantly reminded me, "You are running a marathon, not a race." This line has always resonated with me in times of despair. Although it has been tough to persevere, I ultimately won the battle against my spine.

My curves were close to the extreme range and therefore required bracing. During this time, I was always on edge as my endurance was necessary. Still, going in, I was not fully aware of the difficulty and motivation required to wear a brace. I struggled to adjust my life around wearing this back brace for twenty hours each day for three years, but my curves did not progress into surgery range.

As my personal journey concluded, I became keen on making a difference for patients like myself. I have integrated my love for fashion, my enthusiasm for service, and my curiosity in business as a way to give back. I have designed an "athleisure" wear line with all the proceeds being donated to Setting Scoliosis Straight. The theme of my active wear promotes exercise for anyone running marathon or even a race. This trendy and unique line, Strut for Scoliosis, can be worn by everyone everywhere.

I aspire to spread national and even global awareness about this deformity, as well as raise the funds needed to eradicate it. I hope to brighten the future of my fellow patients and see you all strutting your stuff. Let's Strut for Scoliosis!

- Lindsay Gordon



Lindsay's clothing line
can be purchased on
our website.

www.settingscoliosisstraight.org



Grateful Patient, Caleigh Stednitz, is working hard to ensure that Setting Scoliosis Straight's first-ever patient education course and patient gala will be spectacular events. In May 2016, Power Over Scoliosis and Star Struck are coming to Philadelphia, and Caleigh hopes to see you there!

GRATEFUL PATIENT

Caleigh Stednitz: Lining Up

I was ten years old when I received my brace. I wore it for twenty hours a day with the amount of time gradually decreasing until—two years, two months, and two days later—I no longer was required to wear it. My time in my brace was incredibly difficult; I developed severe depression and anxiety, but I was attached to my brace and terrified that if I took it off, my scoliosis would worsen.

Four years after the brace came off, my curvature had increased dramatically to fifty and thirty-five degrees. I was blown away. The bracing I had suffered through did not work, and I was shocked that I would need a spinal fusion. We decided to wait until my first year of college was finished before performing the procedure.

Recovery was incredibly hard, but I eventually healed and continued on my life's path. During my junior year as a Fibers & Material Studies major, I finally began embracing my scoliosis by creating my first spinal sculpture. From then until I graduated, my art centered solely on scoliosis, the spine, curves, vertebrae, and the hardware associated with a spinal fusion. I created sculptures, digital prints, and most importantly, silkscreened repeat patterns. My work was influenced by my spine's contorted structure.

Using scoliosis to create art became a therapeutic coping mechanism that I still employ today. I have grown to embrace and use my curvature and my experiences growing up as a patient of scoliosis. I still use the spine in my artwork, and I allow the shapes to form patterns for new fabric. 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.

- Caleigh Stednitz



PATIENT STORY

What Story Do You Want to Tell?

Stories have always been invaluable tools in our patient community. They are life lessons passed amongst peers. They are threads that sew one patient to another. Every time a patient with scoliosis shares her story, she lets other patients know they are not alone.

Patient stories represent hope, and this year we added more patient stories than we did in any other year! Thank you, to all of our wonderful patients who aren't afraid to become someone else's guiding voice and comfort!

DEANNE VITIELLO

Nemours Alfred I. duPont Hospital for Children, Delaware

I really feel like the luckiest girl in the world after everything I went through because it shaped me into who I am now! Today, I am almost six years post-op, and I feel absolutely amazing!

The biggest piece of advice I could give anyone reading my story is TRUST. Trust your doctor and your support system, and know that everything will work out the way it is meant to be!



"If you're going to have a story, have a big story, or none at all."

-Joseph Campbell

"Stories make us more alive, more human, more courageous, more loving."

- Madeleine L'Engle



Our patient stories come from many different parts of the country.

Visit our website at www.settingscoliosisstraight.org to read all our patient stories. If you would like to share your story with our community, please contact us at info@ssshsg.org.

BOARD OF DIRECTORS



Peter Newton, MD
Chairman/ President



Dave Clements, MD
Vice President



Robert Stone, CPA
Treasurer



Michelle Marks, PT, MA
Secretary



Baron Lonner, MD



Suken Shah, MD



Randy Betz, MD



Tom Errico, MD



Stacey Goldfarb, Esq.



Kevin Sayar, Esq.



Amer Samdani, MD



Harry Shufflebarger, MD

Departing Board Members



Alvin Crawford, MD

“Having the opportunity to give back both financially and participatory as a board member to Setting Scoliosis Straight as the group moves forward has been great.”

- Alvin Crawford



Stacey Stevens

“Serving on the Setting Scoliosis Straight Board of Directors was a huge honor and privilege. The board is comprised of world-renowned physicians and other professionals who care deeply about helping children and adolescents with spinal deformity. I am fully confident that this group of talented minds and skilled surgeons will continue to transform scoliosis treatment options that enable patients to reach their full potential.”

- Stacey Stevens

INFRASTRUCTURE



Michelle Marks
Executive/Research Director
Born in: New Orleans, LA

Michelle has been with SSS since 1999. She and her husband, Eddie, are proud parents of Max and Lola, who are keep busy with family hikes, surfing, mountain bike riding, and soccer.



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

Jon Marie joined the SSS Team in 2011. As a native Tucsonan, Jon Marie is always game for a DIY project.



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

Maty has been working for SSS since 1999 when he began as a volunteer. When he's not working, Maty stays busy raising two very lucky, very beautiful little girls with his wife, Chloe.



Evan Xanthos
Research Assistant
Born in: Farmington, ME

Evan has been with SSS since 2013. One of his favorite things to do in the community is coach kids.



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

Harvey joined the SSS Team in 2010. Some of Harvey's interests include travel, photography, and roping his co-workers into filming elaborate marriage proposals on Coronado—at night.



Noreen Gaynor
Administrative Assistant
Born in: Jamaica, NY

Noreen has been with SSS since 2014. She isn't afraid to admit that she loves the warm winters in California (sorry, New Jersey), and she's also a fan of shopping and cats.



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

Amy joined the SSS Team in 2011. Outside of work, Amy's greatest passions are writing poetry, chasing sunsets, and having incredibly long philosophical conversations with her dog, Sagan.



Chloe Petcharaporn
Development Manager
Born in: San Diego, CA

Chloe has been with SSS since 2015. A long-standing passion of hers is learning, and she recently found out that she's also really into home-renovating.

VOLUNTEERS

Setting Scoliosis Straight Volunteers Are Love in Motion!

There is no greater act than selflessly helping another. As a not-for-profit foundation, we rely on the kindness of others to bolster our work, further our mission, and lengthen our reach.

This year, we had four new volunteers join us in our work to improve treatment for patients with scoliosis. We are so very thankful for their hard work and time they have donated!

Robin Gordon—Haverford, PA
Star Struck Gala Co-Chair



Robin's work as a Setting Scoliosis Straight volunteer began in 2014, when she and her daughter, Lindsay Gordon, hosted a fundraising event that brought in over \$8,000, all of which was donated to Setting Scoliosis Straight. In 2015, Robin helped model her daughter's athleisure wear line, Strut for Scoli, and she assumed the role of Gala Co-Chair for Setting Scoliosis Straight's very first patient gala, which will take place in May 2016.

Robin's positive impact on Setting Scoliosis Straight and patient outreach is undeniable. Her dedication to improving patient care is making the world a better place!

Jenn Padilla—Levittown, PA
Star Struck Gala Co-Chair

"As a family, we are extremely thankful for the support from the staff at Setting Scoliosis Straight. We look forward to the day when they find a cure for scoliosis and will continue to volunteer our time until that day comes."

- Jenn Padilla



Robert Savich—Aurora, CO
Runner Raising Awareness



How far would you go to raise awareness for scoliosis? Would you travel to Detroit? Would you enter the Detroit Free Press International Marathon and run 26.2 miles? Robert did, and as a patient with scoliosis who has undergone four different spine surgeries, he knows exactly how important raising awareness and improving treatment can be. On October 18th, when Robert crossed the finish line in his Setting Scoliosis Straight t-shirt, he was running to show people how powerful and confident someone can be when they turn a diagnosis into a strength.

Jennifer Wendlant, San Diego, CA
Research Assistant Volunteer

Jennifer began volunteering with Setting Scoliosis Straight in 2015. After hearing about the goals of the foundation from a close friend of hers who works at Setting Scoliosis Straight, Jennifer decided SSS would be a great place to volunteer. Jennifer has been able to help the foundation on multiple levels, including data maintenance and development and outreach. At age 24, Jennifer already knows where she wants to go in life. She plans to become a Naturopathic Doctor and help people via holistic healing methods.



GRATEFUL PATIENT

Jarrood Padilla and his family organized The Super Run to benefit Setting Scoliosis Straight research efforts!



The Padilla family supports Setting Scoliosis Straight at the Super Run in Philadelphia.

Jarrood Padilla is fourteen years old and was diagnosed with scoliosis one year ago. He currently wears a brace but that doesn't stop him from being an avid runner. His mother Jenn, wanting to create a positive experience with scoliosis for Jarrod, reached out to the Super Run organization. Setting Scoliosis Straight was named the host charity thanks in large part to the dedication and commitment of Jenn and the Padilla family to raising scoliosis awareness in their community.

Over a thousand runners participated in the race, including a team organized by Jarrod and his brother Milton Jr., made up of family and friends and aptly named "Races with Braces." Hundreds of race participants visited the Setting Scoliosis Straight booth and learned how scoliosis affects different regions of the spine through a fun, interactive bean bag toss game that Jarrod's dad, Milton constructed.



Jarrood, before the race proudly wearing his Races with Braces team shirt.

Following the event, Jenn remarked how happy Jarrod was to have experienced "giving back" as a patient with scoliosis. With so many challenges associated with Jarrod's diagnosis and bracing treatment, it was wonderful to see him share in the race's success. The foundation is grateful for Jenn, Milton, Milton Jr., and Jarrod. Their passion and efforts put the "super" in the Super Run!



OVER 1,000
Attendees

OVER \$6,000
Raised

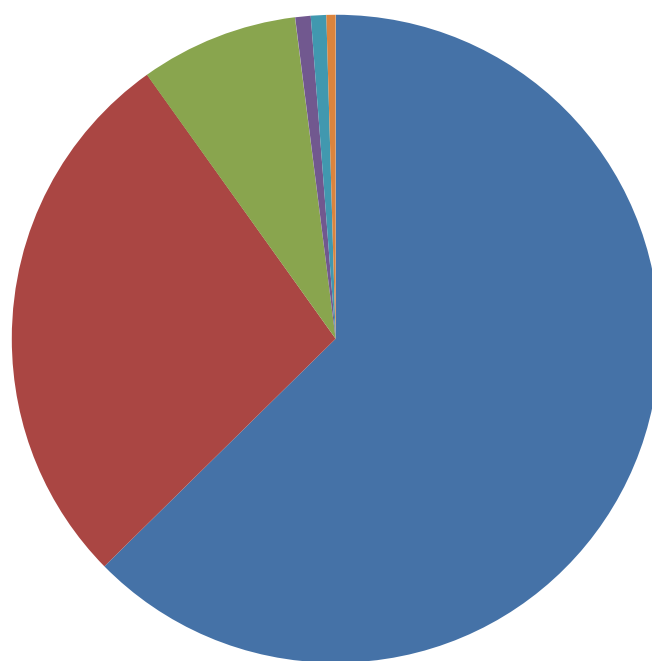


FINANCIAL REPORT

Fiscal Year 2015

Revenue and Support

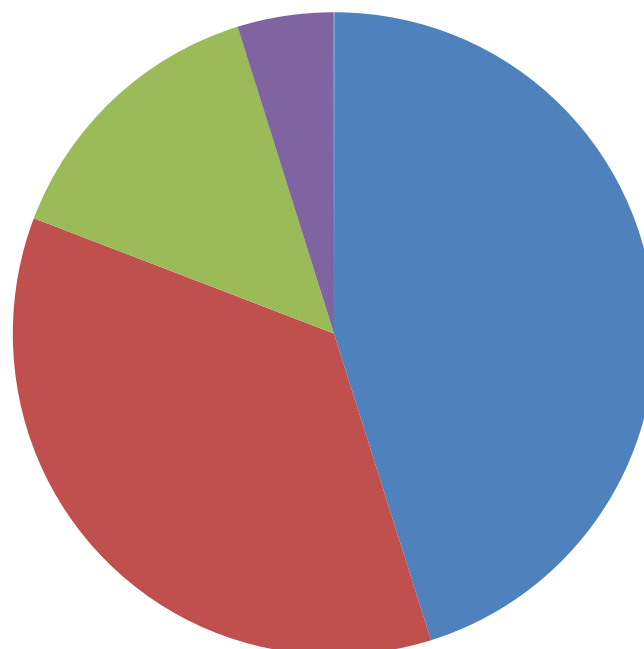
■ Industry & Professional Society Research Grants	\$1,549,418
■ Charitable donations	\$679,745
■ Sponsorships & Course Income	\$195,075
■ Investment Interest	\$19,046
■ Database	\$19,000
■ Consulting	\$11,321



TOTAL REVENUE AND SUPPORT \$2,473,605

Functional Expenses

■ Research Site Reimbursements	\$669,092
■ Research Coordination	\$529,293
■ Management & General	\$212,616
■ Fundraising	\$71,689



TOTAL FUNCTIONAL EXPENSES \$1,482,690

WITH APPRECIATION: 2015 DONORS

Platinum Level: \$20,000 and Above

Randal Betz, MD
Lutz Biedermann
David Clements, III, MD
Thomas Errico, MD
Jeffrey and Stacey Goldfarb
Lawrence Lenke, MD
Lloyd George Foundation
Baron Lonner, MD
Cathy & Peter Newton, MD
Harry Shufflebarger, MD

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

Jahangir Asghar, MD
John M. Flynn, MD
Larry & Camille Ruvo
Suken Shah, MD
Paul Sponseller, MD

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

Patrick Cahill, MD
K2M, Inc.
Stefan Parent, MD
Sig Rogich
Alison & Kevin Sayar
Burt Yaszay, MD

Bronze Level: \$1,000 - \$4,999

Mark Abel, MD
Behrooz and Nasrin Akbarnia
Charles & Gertrude Booth
Alvin Crawford, MD
Peter Gabos, MD
Howard & Andrea Greenberg
James R. Hens
Bo Jamieson
David & Anita Kauffman
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Lauren Krichman
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Firoz Miyanji, MD, FRCSC

Alan Olsen
Joshua Pahys, MD
Amer Samdani, MD
Eric Somers
Robert Stone
Peter Sturm, MD
Faith Read Xenos

Donor: <\$1,000

Emily Aiello
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Fatima Jawad
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Amy Kager
Peter Klein
Theresa Kravcak
Tien Le
Julia Lebovitz
John Lediju
Diane Leichter
John Slebir and Cristina Lupano
Jim Marco
Michelle Marks, PT, MA
Amy Maurizio
Michele McGee
James & Candy McGinley
Danielle McGraw
Bobby Kinwah Ng, MD
Victor Padilla
Jennifer & Milton Padilla
Tracy Phillips
Robert Quinlan
Kurt Risoen
Mark & Maryellen Roberson
Theresa Romero
Michael Rosenburg
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Tamila Sayar
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David L. Sponseller
Anthony Stans, MD
Daniel Sucato, MD, MS
Kristen Venuti
Casey Viera
Barbara P. Wark
Dennis Wenger, MD
Michael White
11 Anonymous

HSG

HARMS STUDY GROUP

Pioneering Research in Spinal Deformities

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

Through comprehensive 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.



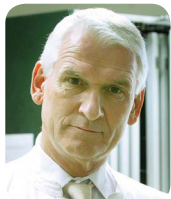
43

HSG SURGEONS

HSG has 43 surgeon members worldwide who perform comprehensive, multi-center prospective research studies focused on pediatric spinal deformity.



EXECUTIVE MEMBERS



Professor Jürgen Harms, M.D.

Chief of Spine Surgery at Klinik Heidelberg Germany; 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.

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, M.D.

Director, Division of Spinal Surgery, Department of Orthopedic Surgery, Miami Children's Hospital, Miami, Florida; Member of The Harms Study Group; SSSF Board Member



Amer F. Samdani, M.D.

Director of the Spine Service at Shriners Hospital for Children, Philadelphia, Pennsylvania; Member of The Harms Study Group; SSSF Board Member



Michelle C. Marks, PT, M.A.

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



CORE MEMBERS

Core members make significant contributions to the main studies of the group. Membership is by invitation of the Executive Committee. The five surgeon members of the Executive Committee are also Core Members of the HSG.



Firoz Miyanji, M.D.
British Columbia Children's Hospital
Vancouver, British Columbia, Canada

Hubert Labelle, M.D.
St. Justine's Montreal Hospital
Montreal, Canada



Stefan Parent, M.D., Ph.D.
St. Justine's Montreal Hospital
Montreal, Canada



Randal R. Betz, M.D.
The Institute for Spine & Scoliosis
Lawrenceville, New Jersey



Peter Newton, M.D.
Rady Children's Hospital
San Diego, California



Burt Yaszay, M.D.
Rady Children's Hospital
San Diego, California

David Clements, M.D.
Cooper Bone & Joint Institute
Philadelphia, Pennsylvania



Amer F. Samdani, M.D.
Shriners Hospital for Children
Philadelphia, Pennsylvania



Patrick J. Cahill, M.D.
Children's Hospital of Philadelphia
Philadelphia, Pennsylvania



Jack Flynn, M.D.
Children's Hospital of Philadelphia
Philadelphia, Pennsylvania

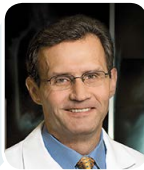




Dan Hedequist, M.D.
Boston Children's Hospital
Boston, Massachusetts



Michael Glotzbecker, M.D.
Boston Children's Hospital
Boston, Massachusetts



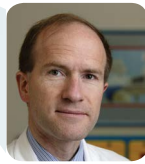
Lawrence Lenke, M.D.
Columbia University
New York, New York



Baron Lonner, M.D.
Mount Sinai Hospital
New York, New York



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Wilmington, Delaware



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Baltimore, Maryland



Harry Shufflebarger, M.D.
Miami Children's Hospital
Miami, Florida



John Asghar, M.D.
Miami Children's Hospital
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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.

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Cincinnati, Ohio

Dennis Wenger, M.D.
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San Diego, California

RESEARCH PRODUCTIVITY

Year	Podium Presentations*	Poster Presentations*	Manuscripts Published^
2010	28	26	6
2011	27	34	14
2012	23	27	12
2013	22	16	14
2014	29	16	13
2015	32	13	15

*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 2015, The Harms Study Group presented a total of forty-five podiums and posters at medical conferences, and our members had a total of fifteen manuscripts published in scientific journals.



Being a part of HSG has allowed me to be mentored by 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 when taken together, often result in a solution.

- Amer F. Samdani, M.D.

2015 Surgeon Member Highlights



Randal Betz, MD, a founding member of the Harms Study Group and board member of Setting Scoliosis Straight, was honored this year with the Lifetime Achievement Award at the Scoliosis Research Society's 50th annual meeting in Minneapolis, Minnesota. The breadth of Dr. Betz's many professional accomplishments were applauded. We congratulate Randy on this special honor and are grateful for his commitment to our study group and foundation.

Dennis Wenger, MD, a Harms Study Group Emeritus Member, was an honored speaker at the Scoliosis Research Society's 50th annual meeting where he delivered a riveting speech on the history and evolution of scoliosis care.



Stefan Parent, MD, Burt Yaszay, MD, and Patrick Cahill, MD, all participated in the Scoliosis Research Society Traveling Fellowship Program. Their three week program included visiting several leading spine deformity centers throughout Asia.

Emeritus Member: Alvin Crawford, MD

"I very much enjoyed my association with HSG, and was most impressed with the open invitation not limiting me to a particular implant so long as I shared all data. This was unusual for membership in industry sponsored groups at the time. I may have been one of the last busy spine surgeons to use a hybrid system as pedicle screws were becoming the norm. The camaraderie and scientific approach to collaborative studies we carried out were innovative and are now state of the art. We participated in the creation of the Frontier Vertebral Body Screw to aid success in the management of AIS by Video Assisted Thoracic Surgery. While the meetings were extremely focused in intense scientific research, the realization of the practical joker expertise of a fellow past president of SRS was enlightening to me and was a tremendous stress reliever at the end of a busy day. The friendships developed during my time and seeing the administrative advancement to responsibility of younger members of the group in the SRS is exciting. Additionally I had the opportunity to share many modern jazz tunes with recording star Tony Gulizia in a packed bar when we were at the Pines Lodge. It was flattering at hotel check-in to have the staff ask if we were playing that night. (Smile) I finally have the opportunity to give back both financially and participatory as a board director to SSS as the group moves forward. It's been great."



- Alvin Crawford, MD

CEREBRAL PALSY STUDY

Primary investigator, **Paul Sponseller, MD**, from Baltimore leads this important study. Through support of **Depuy Synthes Spine** and now **K2M, Inc.**, this study has developed into an ongoing registry.

Some highlights from the 2015 research efforts associated with this study include:

- An association between the neuromotor classification GMFCS-5, which signifies impairments in all areas of function, and health related quality of life scores and severity of Scoliosis in CP was identified.
- The three most common causes of re-operation in patients with Cerebral Palsy include infection, proximal junctional kyphosis and instrumentation prominence/loosening.
- Patients with Cerebral Palsy experience reduced back pain after surgery for scoliosis.

Our research sites have enrolled CP patient since 2008. Patients are followed for up to five years after their surgical or baseline visit.

121
non-operative patients

438
operative patients

CP PATIENT STORY

Izzy Kessler, now 20 years old, was born with Cerebral Palsy. In 8th grade, her scoliosis became so severe that surgery was necessary and the surgery was able to completely straighten her spine and give her perfect posture!

Izzy is an athlete, a high school graduate, a coach, and a mentor who began her athletic career early. In high school, she was the captain of her high school's co-ed bocce team, which won the Maryland State Championship. She now coaches that team, and she volunteers two days a week at a hospital to mentor inpatient pediatric patients.



ADOLESCENT IDIOPATHIC SCOLIOSIS STUDY

Crucial ongoing support from **DePuy Synthes Spine, Inc.** allows our Adolescent Idiopathic Scoliosis (AIS) Database Registry to remain the largest prospective database of its kind. With over 4500 patients enrolled, this powerful dataset enables primary investigator, **Peter Newton, MD** the ability to lead our surgeon members in answering important clinical questions.

Some of the discoveries from our 2015 efforts that were used to educate surgeons across the globe include:

- Obesity increases the risk of deep surgical site infections and implant failure in posterior spinal fusion patients.
- Two year follow-up is not long enough follow-up in spinal fusion patients.
- Patients with mature bones and untreated scoliosis may have small increases in their curves and decreases in health-related quality of life.
- Low rates of revision surgeries still occur five years after initial surgeries.

In 2015, two abstracts dealt specifically with improving care worldwide. We found that:

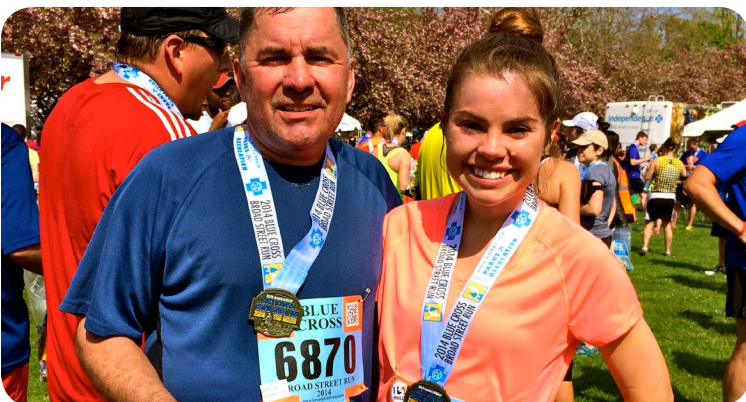
- Three-year surgeon performance dashboard reports significantly improved amounts of blood loss and operating time in AIS surgeries.
- Adoption of standardized care pathways reduced length of stay in AIS patients.

We will continue progressing with ongoing assessments of surgeon performance measures as we identify more areas of care. The establishment of Best Practice Guidelines will remain at the forefront for our efforts into 2016.

Our research sites have enrolled AIS patients since 1995, with the goal of tracking patients for 25 years after their surgeries.

440
non-operative patients

4538
operative patients



AIS patient Elizabeth Conklin, completed a ten-mile race.

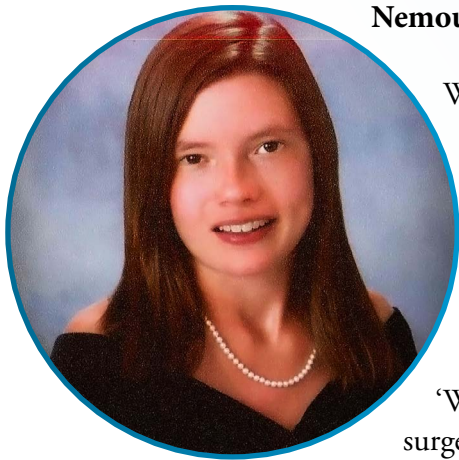
AIS PATIENT STORIES

Each patient who has spinal surgery has a unique story to tell. Reading inspirational stories from patients who have had spinal surgery may help you and others like yourself find the support and comfort they need.



ANNA O'CONNOR

Nemours Alfred I. duPont Hospital for Children, Delaware



When I was eight years old I was diagnosed with scoliosis, and I had to wear a brace. For years, I didn't want people to know about my scoliosis. It was a struggle balancing between my brace, my appointments, and all the activities going on. When I reached high school, decided to stick with band. I did not have any restrictions, although I still worried about the brace and how it was affecting me, but when my friends finally found out about my scoliosis, they were extremely supportive.

During my sophomore year in high school, Dr. Shah recommended spinal fusion surgery. The thought of surgery was stuck in my head for days. I just kept thinking, 'Why me? Why does this have to happen to me?' Others have had to undergo spinal surgery, though, and one of those families helped mentor me and my family through our experience. My spinal surgery actually made me stronger and more confident. It shaped me into the person I am today, and Dr. Shah has influenced me to become a music therapist. When I go to the hospital now, I see other patients and kids that I want to help.

ELIZABETH CONKLIN

Nemours Alfred I. duPont Hospital for Children, Delaware

When I was first diagnosed, I had no idea what would be in store for me, but looking back, I think I had the ultimate scoliosis experience. I wore a brace sixteen hours a day for three years, but after four years of not wearing my brace, I began to see changes in the way my body looked. During my senior year of high school, my doctor told me that spinal fusion surgery was necessary. After eight hours of surgery, I had two rods and twenty-four screws in my spine. I finally had a spine with minimal curves, I grew two inches in the process, and after seven months, I was able to snowboard again as if I didn't even have titanium in my back!



VALERIE CHAPMAN

Miami Children's Hospital



My epic journey with scoliosis gave me an incredible sense of pride. I was thirteen when I was diagnosed. Wearing a brace wasn't an option. The only thing I could do was have surgery, and I'll never forget what it felt like when I discovered that this would be the only way to fix my condition. On April 2nd, 2013, one week after spring break, I had spinal fusion surgery. I spent seven days in the hospital and missed a month of my last year of middle school in order to recover. Recovery was the hardest part of my journey with scoliosis, but my doctor, nurses, and the caring staff at Miami Children's Hospital gave me another chance to feel confident with my body. I'd always dreamt of becoming a model and at just sixteen years old, I signed with two modeling agencies in New York and Miami. Please don't let scoliosis stop you from following your dreams! Scoliosis is part of who I am, but I won't let it define me.

HELENA ROBERTS

Miami Children's Hospital

Diagnosed with scoliosis at age eleven, I was quite unaware of the long journey I had ahead of me. It seemed that with every visit to the doctor, the degree of my curves worsened, and the plausibility of surgery increased significantly. I tightened the straps of my brace and prayed that I would be spared the inevitability of surgery, so that I could continue pursuing my passion for ballet. Five years after my diagnosis, I decided to undergo surgery. Two rods and twenty-two screws later, the curves of my spine decreased considerably, and only nine months after surgery, I performed in the ballet, *Sleeping Beauty*, as if I'd never undergone surgery! Despite my previous doubts, I am amazed with my current levels of mobility and flexibility.

Having surgery was undeniably the right decision for me.



2015 SCIENTIFIC PUBLICATIONS

1. Miyanji F, Newton PO, Samdani AF, Shah SA, Varghese RA, Reilly CW, Mulpuri K. Impact of Surgical Waiting List Times on Scoliosis Surgery: The Surgeon's Perspective. *Spine (Phila Pa 1976)* 40(11):823-8, Jun. 1, 2015
2. Samdani AF, Asghar J, Miyanji F, Bennett JT, Hoashi JS, Lonner BS, Marks MC, Newton PO, Betz RR. Recurrence of Rib Prominence Following Surgery for Adolescent Idiopathic Scoliosis with Pedicle Screws and Direct Vertebral Body Derotation. *Eur Spine J*. 24(7):1547-1554, July 2015.
3. Cahill PJ, Steiner C, Dakwar E, Lonner BS, Newton PO, Shah SA, Sponseller PD, Shufflebarger HL, Samdani AF. Sagittal Spinopelvic Parameters in Scheuermann's Kyphosis. A Preliminary Study. *Spine Deform* 3(3):267-71, May 2015.
4. Jain A, Sponseller PD, Negrini S, Newton PO, Cahill PJ, Bastrom TP, Marks MC, Harms Study Group. SRS-7: A Valid, Responsive, Linear, and Unidimensional Functional Outcome Measure for Operatively Treated Patients with AIS. *Spine (Phila Pa 1976)* 40(9):650-5, May 1, 2015.
5. Yaszay B, Scannell BP, Bomar JD, Sponseller PD, Shah SA, Asghar J, Samdani AF, Bastrom TP, Newton PO, Harms Study Group. While Inconvenient, Baclofen Pumps Do Not Complicate Scoliosis Surgery in Patients with Cerebral Palsy. *Spine (Phila Pa 1976)* 40(8):E504-9, Apr. 15, 2015.
6. Marks MC, Bastrom TP, Petcharaporn M, Shah SA, Betz RR, Samdani A, Lonner B, Miyanji F, Newton PO. The Effect of Time and Fusion Length on Motion of the Unfused Lumbar Segments in Adolescent Idiopathic Scoliosis (AIS). *Spine Deform* 3:549-53, 2015.
7. Lonner B, Toombs CS, Husain QM, Sponseller P, Shufflebarger H, Shah SA, Samdani AF, Betz RR, Cahill PJ, Yaszay B, Newton PO. Body Mass Index in Adolescent Spinal Deformity: Comparison of Scheuermann's Kyphosis, Adolescent Idiopathic Scoliosis, and Normal Controls. *Spine Deform* 3(4):318-26, July 2015.
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9. Sponseller PD, Jain A, Newton PO, Lonner BS, Shah SA, Shufflebarger HL, Bastrom TP, Marks MC, Betz RR. Posterior Spinal Fusion With Pedicle Screws in Patients With Idiopathic Scoliosis and Open Triradiate Cartilage: Does Deformity Progression Occur? *J Pediatr Orthop*. 2015 Jun 17. [Epub ahead of print]
10. Lonner BS, Toombs CS, Guss M, Braaksma B, Shah SA, Samdani A, Shufflebarger H, Sponseller P, Newton PO. Complications in Operative Scheuermann's Kyphosis. Do the Pitfalls Differ from Operative Adolescent Idiopathic Scoliosis? *Spine (Phila Pa 1976)* 40(5):305-11, Mar. 2015.
11. Jain A, Sponseller PD, Newton PO, Shah SA, Cahill PJ, Njoku DB, Betz RR, Samdani AF, Bastrom TP, Marks MC, Harms Study Group. Smaller Body Size Increases the Percentage of Blood Volume Lost During Posterior Spinal Arthrodesis. *J Bone Joint Surg Am* 97(6):507-11, Mar. 18, 2015.
12. Arunakul R, Peterson A, Bartley CE, Cidambi KR, Varley ES, Newton PO. The 15-year Evolution of the Thoracoscopic Anterior Release: Does it Still Have a Role? *Asian Spine J* 9(4):553-8, Aug. 2015.

2015 SCIENTIFIC PRESENTATIONS



AAOS
AMERICAN ACADEMY OF ORTHOPAEDIC SURGEONS

POSNA

SRS 10 podiums 6 posters

IMAST 11 podiums

POSNA 5 podiums 6 posters

AAOS 6 podiums 1 poster

13. Bastrom TP, Bartley C, Marks MC, Yaszay B, Newton PO, Harms Study Group. Postoperative Perfection: Ceiling Effects and Lack of Discrimination with Both SRS-22 and 24 Outcomes Instruments in Adolescent Idiopathic Scoliosis Patients. Spine (Phila Pa 1976) 40(24):E1323-9, Dec. 2015
14. Samdani AF, Belin EJ, Bennett JT, Miyajima F, Pahys JM, Shah SA, Newton PO, Betz RR, Cahill PJ, Sponseller PD. Major Perioperative Complications After Spine Surgery in Patients With Cerebral Palsy: Assessment of Risk Factors. Eur Spine J. 2015 Jul 7. [Epub ahead of print]
15. Cidambi KR, Glaser D, Doan J, Newton PO. Generation of a Patient-Specific Model of Normal Sagittal Alignment of the Spine. Spine Deform 3(3):228-32, May 2015.



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DePuy Synthes Spine Canada,
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