



*Supporting Discoveries in Spinal Deformities*



# 2019 ANNUAL REPORT

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

Setting Scoliosis Straight is a non-profit 501(c)(3) organization devoted to empowering families impacted by scoliosis through education, connection, and research

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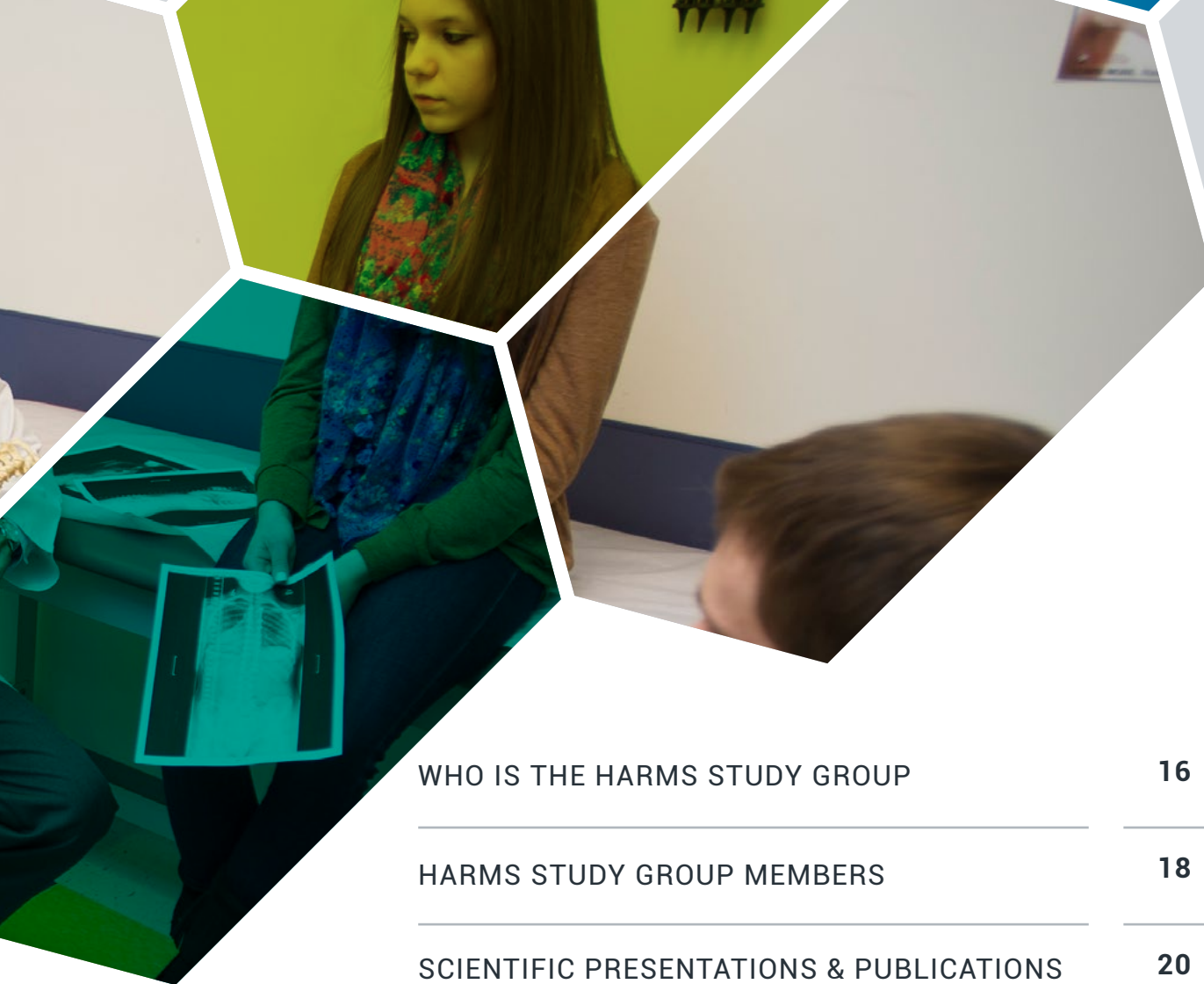
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Dr. Suken Shah with  
patient & family



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## DEAR FRIENDS,

We are proud to offer you the 2019 Annual Report, reflecting the collaborative efforts and accomplishments of the Setting Scoliosis Straight Foundation and the Harms Study Group. We remain dedicated to the mission of advancing the treatment of scoliosis and spinal deformity in children via research and education. In 2019, our research facilitated new discoveries that will change future patient outcomes for the better. Our network has grown to encompass 35 of the world's top scoliosis surgeon researchers. More importantly, our scientific discoveries have been disseminated to thousands of physicians and surgeons through dozens of international scientific presentations and manuscript publications.

Patient education remains a top priority with the goal of bringing evidence-based knowledge to our patients and families. Both online material and live courses have reached hundreds of newly diagnosed patients and families in stressful times of need. We are listening - and directing our research toward getting the answers you need. I cannot thank the Foundation Family enough for their continued support in our endeavors.

The pages that follow will give you a glimpse into the busy year of 2019 and focus our attention on all that remains to be done in 2020! We appreciate your trust, support and dedication to our shared vision.

**Peter Newton, MD**

President, Setting Scoliosis Straight

# DEAR SCOLIOSIS FAMILY,

2019 was filled with **promising** research discoveries, unparalleled **growth** in quality improvement efforts, and crucial discussions through patient engagement – we are honored to continue this collaborative journey and celebrate our progress with all of you!

With our study group leading the way in **vital outcomes research** for the newly approved Anterior Spinal Growth Tethering procedure, we are empowered to begin a research effort with the FDA aimed at better understanding patient preferences surrounding treatment options.

Our **Surgeon Performance Program** quality improvement initiative has grown exponentially, with over 80 surgeon participants receiving comparative dashboard reports focused on improving patient care through self-assessment.

Our 5th annual **Power Over Scoliosis** patient education course engaged many patients and families in the Baltimore area, and we are thankful for the generous community support!

Our annual accomplishments would not be possible without support from dedicated sponsors and donors like you. We look to 2020 with inspiration from our scoliosis patients, whose strength to persevere despite obstacles gives us fuel to keep moving full speed ahead!



**Michelle Marks, PT, MA**

Executive Director,  
Setting Scoliosis Straight





patients sharing their scars



Supporting Discoveries in Spinal Deformities

## THE FOUNDATION DIVISION

The Setting Scoliosis Straight Foundation (SSSF) is a not-for-profit charitable foundation established in 2008 to support the research efforts of the Harms Study Group. As the **Foundation Division** of the organization, it focuses on fundraising, awareness, patient education and improving quality in care.

“

*When my daughter was diagnosed with scoliosis, I spent hours and hours on the internet looking for information and it was so clear to me when I stumbled upon Setting Scoliosis Straight. What a wonderful community and family it is and how it helped us get through this journey.*

- Jen May  
Scoliosis Parent

# WHAT WE DO



## RESEARCH

Clinical research is a critical and mandatory component to advance and improve scoliosis treatment. But financing research is costly and it is becoming harder to fund, which is why a major focus of the SSSF is to support the research efforts of the Harms Study Group.



## EDUCATION

Patient education is essential to a family's well-being, so we created **Power Over Scoliosis**: an annual educational event bringing together orthopedic experts and patient ambassadors to share their insights, while providing families with the educational tools to make clear, confident decisions regarding future treatment and care.




## SUPPORT

Change happens when BIG ideas are supported by lots of small efforts.

Due to the collective efforts of scoliosis ambassadors from all over the country, we are empowering and advocating on behalf of children living with spinal deformities.

Become an SSS ambassador today and use your talents and skills to help others!





Annual Meeting of  
Harms Study Group

## OUR BOARD OF DIRECTORS



**PETER NEWTON, MD**  
President & Chairman



**DAVID CLEMENTS, MD**  
Vice President



**ROBERT STONE, CPA**  
Treasurer



**MICHELLE MARKS, PT, MA**  
Secretary





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**LAWRENCE LENKE, MD**



**BARON LONNER, MD**



**AMER SAMDANI, MD**



**KEVIN SAYAR, Esq.**



**SUKEN SHAH, MD**



**HARRY  
SHUFFLEBARGER, MD**

## DEPARTING BOARD MEMBER



*It was a true honor to serve on the Setting Scoliosis Straight Board of Directors and work with the esteemed spine surgeons of the Harms Study Group (HSG). My hope is that additional spine industry colleagues will experience how this foundation provides the best scoliosis patient education in the world and that the HSG provides research unparalleled by any other spine society.*

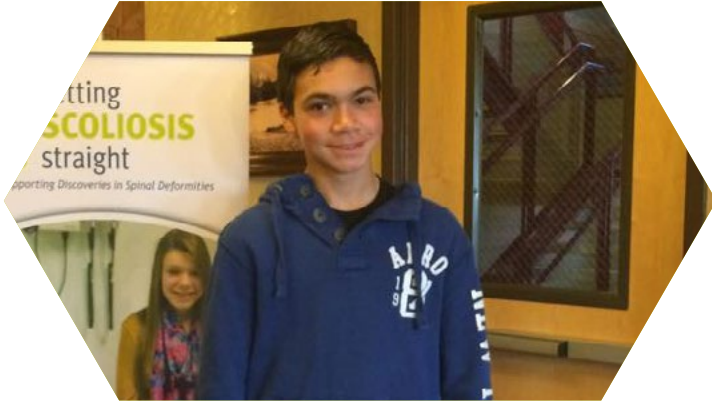


- **ALAN OLSEN**

Founder of Danek Medical, Inc.

# GET INVOLVED HOW YOU CAN HELP...

Are you interested in getting involved with us to help improve scoliosis treatment and create scoliosis awareness? There are many ways you can get involved with Setting Scoliosis Straight.



## YOU CAN MAKE A DIFFERENCE BY BECOMING A:

- ✓ Scoliosis Ambassador
- ✓ Scoliosis Spokesperson
- ✓ Volunteer
- ✓ Social Media Advocate



## TO GET STARTED:

Visit our website for more information on how you can get involved with our foundation.



[www.settingscoliosisstraight.org](http://www.settingscoliosisstraight.org)



**1 PERSON IS ALL IT  
TAKES TO MAKE A  
DIFFERENCE**

# PATIENT STORY

## TANYA KRUEGER

My name is Tanya Krueger and I was born with Congenital Scoliosis. I was also born with Spina Bifida which turned out to be very minor, compared to the severity of my Scoliosis. My curve at birth was around 55 degrees. They tried body cast, bracing, and I saw a specialist weekly. My parents took me to Shriners in Chicago. One surgery turned into two. Once inside the doctors found my spine was much worse than anticipated. I was trached at age four and placed on a ventilator at night at age 7. My lungs are very small, and I easily would get lung infections. I was also on oxygen until my late teen years. With the nighttime ventilator support, my lungs became stronger and my health more stable.

My lungs and heart took a beating and I spent my childhood in the hospital, many times near death. I currently, have a curve of well over 100 degrees. I stand just 4ft tall, due to the surgeries and the curve. I still have a trach and a vent, but am able to drive, own a home, and do volunteer work in the community.

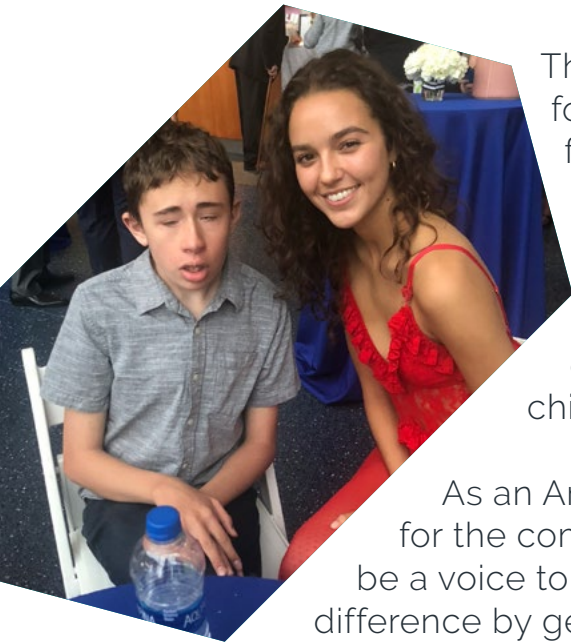


To read Tanya's full story,  
visit our website at:

[www.settingscoliosisstraight.org](http://www.settingscoliosisstraight.org)



# AMBASSADOR PROGRAM



The **Setting Scoliosis Straight Ambassadors** are a voice for creating awareness. They are advocates who raise funds to support our research and education programs.

Change happens when big ideas are manifested through small efforts. At Setting Scoliosis Straight, Ambassadors from all over the country are empowering others and advocating on behalf of children living with spinal deformities.

As an Ambassador, you are willing to give your time and talents for the common good, create awareness in your community and be a voice to those suffering with spinal deformities. You can make a difference by getting involved with Setting Scoliosis Straight.

## THERE ARE MANY WAYS TO GET INVOLVED AS A SCOLIOSIS AMBASSADOR:

- ✓ Become a Brand Ambassador
- ✓ Engage on Social Media
- ✓ Educate the Community
- ✓ Volunteer at Events
- ✓ Start a Fundraiser
- ✓ Mentor Scoliosis Patients



Visit our website to learn now to become a Scoliosis Ambassador

[www.settingscoliosisstraight.org](http://www.settingscoliosisstraight.org)



# FOUNDATION FAMILY

At Setting Scoliosis Straight, families remain at the core of everything we do 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—comprised of grateful families and caring friends who want to come together to raise awareness and support a cause that has been severely underrepresented. What started as a small group of eager volunteers has transformed into a nationwide network of over 500 Foundation Family members!



For more information, visit our website today!

[www.settingscoliosisstraight.org](http://www.settingscoliosisstraight.org)



2019 Power Over Scoliosis

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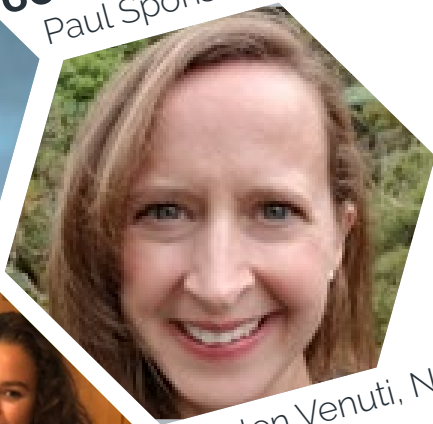
# PATIENT EDUCATION **POWER OVER SCOLIOSIS**

Our annual education event, **Power Over Scoliosis** was held in Baltimore, Maryland in 2019. This course offered the opportunity for patients and families to learn about evidence-based treatment options for spinal deformities. It also brought together the best and brightest in the orthopedic industry along with scoliosis patients and families from all over the country to learn from each other's personal experiences and lean on one another for support.

Special thanks to everyone who supported this event! Your presence and contributions demonstrated the need for continuous patient education and spinal research.



**CO-CHAIRS**  
Paul Sponseller, MD



Kristen Venuti, NP

## SPECIAL THANKS



# 19

## FUNDRAISER GIVE BACKS HOPE

Give Backs Hope is an event that brings families from all over the country together for an evening of fundraising for the advancement of spinal deformity treatment.

This year, medical professionals, grateful patients and families and community leaders assembled at the Maryland Science Center to raise awareness and fundraising support for pediatric spine research. Special thanks to all our guest speakers: Lt Governor Boyd Rutherford, SSSF spokeswoman, Emm Arruda, and guest performer, Cole Moran of BlindWind.

### TO ALL OUR SPONSORS



GREEN SUN  
MEDICAL



Cole Moran





Paul Sponseller, MD  
HSG Member



## THE RESEARCH DIVISION

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

As the **Research Division** of the organization, the study group is dedicated to answering important clinical questions regarding treatment approaches, techniques, and best practices. All research is performed with the ultimate goal of improving patient outcomes.



*It is an unbelievable privilege to be part of the Harms Study Group. There really is nothing else like it. I am able to share ideas, learn, and think with a group of individuals that move the needle in scoliosis care every day. I leave every meeting energized by the shared passion and dedication to patient care. The Harms Study Group makes me a better surgeon and researcher, and I know that means that we are consistently improving the care we can deliver to our patients.*

# WHAT **WE DO**



## OUR MISSION

The Setting Scoliosis Straight Foundation and The Harms Study Group work together to support discoveries and advance techniques, in the treatment of children and adolescents with spinal deformities worldwide.



## OUR COMMITMENT

Through parent education, physician education, and multi-center clinical research, we provide the latest education on spinal deformity treatment and surgical treatment techniques to patients, patient families, surgeons, and healthcare providers.



## OUR VISION

Through high quality research, we envision a future where children and adolescents with spinal deformities will have the ability to live healthy, happy, and productive lives.

Larry Lenke, MD in the operating room.



# HSG MEMBERS

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



**Peter Sturm, MD**  
Cincinnati Children's  
Hospital  
Cincinnati, Ohio



**Randal Betz, MD**  
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**David Clements, MD**  
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**Keith Bachmann, MD**  
University of Virginia  
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**Steven Hwang, MD**  
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Pennsylvania



**Peter Newton, MD**  
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Hospital San Diego,  
California



**Munish Gupta, MD**  
Washington University  
St. Louis, Missouri



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



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



**Michael Kelly MD**  
Washington University  
St. Louis, Missouri



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



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



**Daniel Sucato, MD**  
Texas Scottish  
Rite Hospital



## EMERITUS MEMBERS

**Alvin Crawford, MD**  
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Cincinnati, Ohio

**Dennis Wenger, MD**  
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San Diego, California

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**Stefan Parent, MD, Ph.D.**  
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**Jean-Marc Mac-Thiong, MD**  
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**Lawrence Lenke, MD**  
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New York, New York



**Michael Vitale, MD**  
Columbia University  
New York, New York



**Ben Roye, MD**  
Columbia University  
New York, New York



**Baron Lonner, MD**  
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**Aaron Buckland, MD**  
New York University  
New York, New York



**Suken Shah, MD**  
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duPont Hospital for  
Children Wilmington,  
Delaware



**Peter Gabos, MD**  
Nemours Alfred I.  
duPont Hospital for  
Children, Wilmington,  
Delaware



**Paul Sponseller, MD**  
Johns Hopkins  
Hospital Baltimore,  
Maryland



**Amit Jain, MD**  
Johns Hopkins Hospital  
Baltimore, Maryland



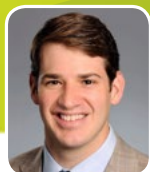
**Harry Shufflebarger, MD**  
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Florida



**John Asghar, MD**  
Paley Orthopedic and  
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Florida



**Michael Glotzbecker, MD**  
Rainbow Babies &  
Children's Hospital  
Cleveland, Ohio



**Nicholas Fletcher MD**  
Emory Orthopaedics & Spine  
Atlanta, Georgia

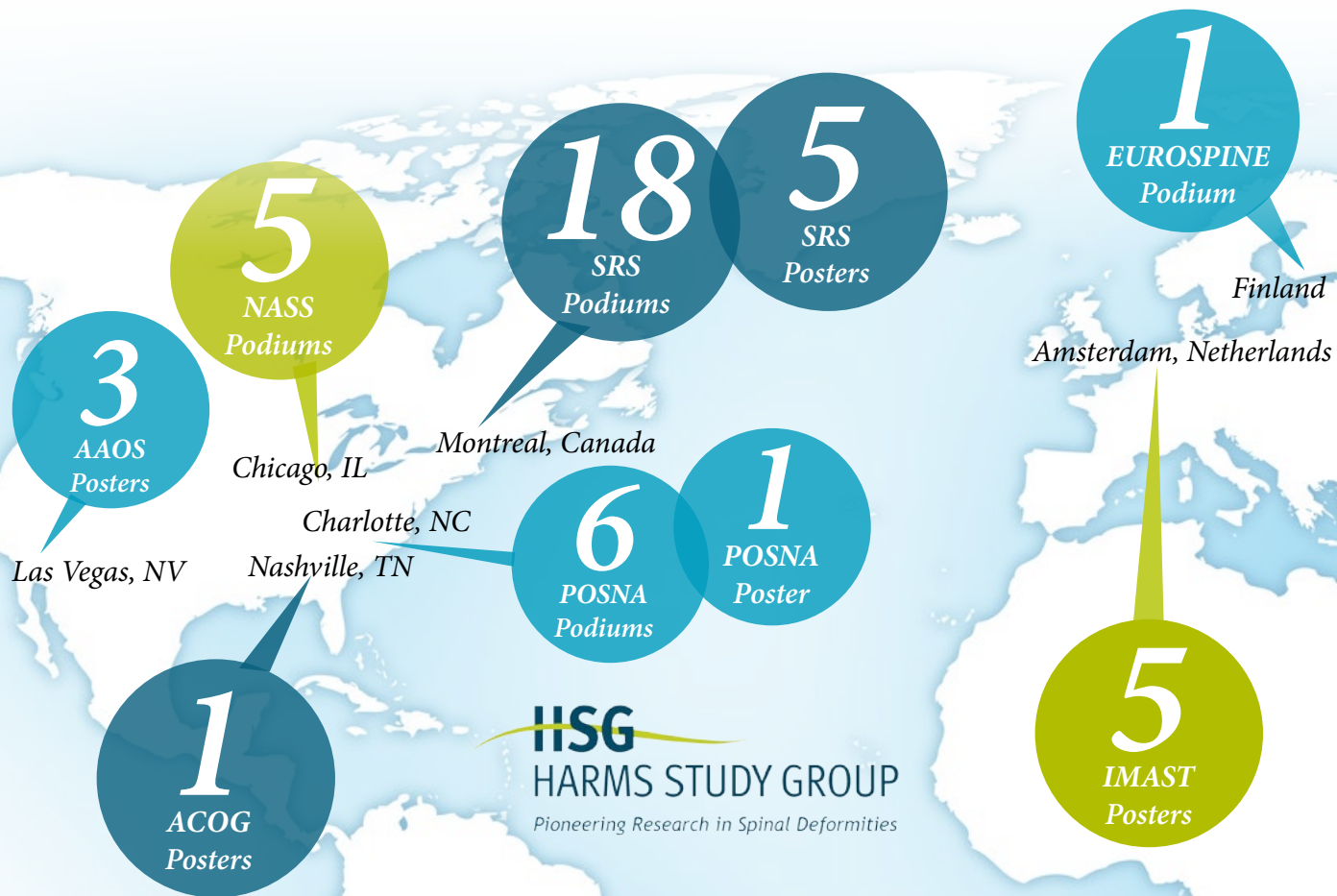


**Tom Errico, MD**  
Nicklaus Children's  
Hospital Miami, Florida



**Stephen Goerge, MD**  
Nicklaus Children's  
Hospital Miami, Florida

# 2019 SCIENTIFIC PRESENTATIONS



## TRAVELING AROUND THE WORLD!

The Harms Study Group had a huge presence this year at seven major annual scientific meetings and courses. These courses allow surgeons from all across the world to share their research findings and ultimately foster the optimal care of all patients with spinal deformities.



# 2019 SCIENTIFIC PUBLICATIONS

1. **Lonner BS**, et al. [Surgery for adolescent idiopathic scoliosis patients after skeletal maturity: early vs. late surgery](#). Spine Deform. 2019 Jan;7(1):84-92.
2. Brooks JT, **Yaszay B**, et al. [Do All Patients With Cerebral Palsy Require Postoperative Intensive Care Admission After Spinal Fusion?](#) Spine Deform. 2019 Jan;7(1):112-117.
3. Hollenbeck SM, **Yaszay B**, [The pros and cons of operating early vs. late in the progression of CP scoliosis](#). Spine Deform. 2019 May;7(3):489-493.
4. **Burt Yaszay, MD**, et al. [Progressive Decline in Pulmonary Function 5 Years Post-Operative in Patients Who Underwent Anterior Instrumentation for Surgical Correction of Adolescent Idiopathic Scoliosis](#). Eur Spine J. 2019 Jun;28(6):1322-1330.
5. Lee Phillips, MD; **Burt Yaszay, MD**, et al. [L3 Translation Predicts When L3 is Not Distal Enough for an "Ideal" Result in Lenke 5 Curves](#). Eur Spine J. 2019 Jun;28(6):1349-1355.
6. **Newton, PO**. et al. [What Factors Are Associated With Kyphosis Restoration in Lordotic Adolescent Idiopathic Scoliosis Patients?](#) Spine Deform. 2019 Jul;7(4):596-601.
7. **Michael P Kelly**, MD et al. [The Minimum Detectable Measurement Difference for the Scoliosis Research Society-22r in Adolescent Idiopathic Scoliosis: A Comparison with the Minimum Clinically Important Difference](#). Spine J. 2019 Aug;19(8):1319-1323.
8. **Jean-Marc Mac-Thiong, MD, PhD**, et al. [Criteria for Surgical Reduction of High-Grade Lumbosacral Spondylolisthesis Based on Quality of Life Measures](#). Eur Spine J. 2019 Sep;28(9):2060-2069.
9. Alzakri, A., **Mac-Thiong, JM**. [Restoration of normal pelvic balance from surgical reduction of high-grade spondylolisthesis](#). Eur Spine J. 2019 Sep;28(9):2087-2094.
10. Koller, **Newton PO** et al. [Prediction of spontaneous lumbar curve correction following posterior selective thoracic fusion in adolescent idiopathic scoliosis using logistic regression models and clinical rationale](#). Eur Spine J. 2019 Sep;28(9):1987-1997.
11. Usmani MF, **Shah SA**, et al. [The role of cross-links in posterior spinal fusion for cerebral palsy-related scoliosis](#). Spine (Phila Pa 1976). 2019 Nov 1;44(21):E1256-E1263.
12. Toombs C, **Lonner B**, et al. [The Adolescent Idiopathic Scoliosis International Disease Severity Study: Do Operative Curve Magnitude and Complications Vary by Country?](#) Spine Deformity. 2019 Nov 7; 7(6): 883-889.
13. Bastrom TP, **Newton PO**, et al. [Patient-Reported SRS-24 Outcomes Scores After Surgery for Adolescent Idiopathic Scoliosis Have Improved Since the New Millennium](#). Spine Deform. 2019 Nov;7(6):917-922.
14. **Hwang**, et al. [Lower SRS Mental Health Scores are Associated With Greater Preoperative Pain in Patients With Adolescent Idiopathic Scoliosis](#). Spine (Phila Pa 1976). 2019 Dec 1;44(23):1647-1652.
15. **Newton PO**, et al. [The 3D Sagittal Profile of Thoracic Versus Lumbar Major Curves in Adolescent Idiopathic Scoliosis](#). Spine Deform. 2019 Jan;7(1):60-65.
16. **Jain A**, et al. [Cost-utility analysis of operative versus nonoperative treatment of thoracic adolescent idiopathic scoliosis](#). Spine (Phila Pa 1976). 2019 Mar 1;44(5):309-317.



# CEREBRAL PALSY SCOLIOSIS STUDY

## A PROSPECTIVE DATABASE REGISTRY STUDY

Grateful acknowledgement to our sole sponsor of this research study: **Stryker/K2M, Inc.**

Leading the charge for this study is primary investigator, **Paul Sponseller, MD**, who is the Chief of the Division of Pediatric Orthopaedics at Johns Hopkins Children's Center. Dr. Sponseller has been a member of the Harms Study Group since 2004.

OPERATIVE PATIENTS  
DATA COLLECTED

666

18

RESEARCH SITES &  
HOSPITALS PARTICIPATING

142

NON-OPERATIVE PATIENTS  
DATA COLLECTED

# CEREBRAL PALSY SCOLIOSIS RESEARCH DISCOVERIES IN 2019

*Research findings presented at Scoliosis Research Society Annual Meeting*

**Positive effects of Posterior Spinal fusion in children with Cerebral Palsy:** Drs. Pat Cahill & Keith Baldwin studied the change in weight percentile in patients and found that corrective spinal surgery may improve weight percentile in patients who start out at 50th weight percentile and lower.

**Spinal Alignment after spinal fusion and worsening hip status in Cerebral Palsy children:** Dr Aaron Buckland evaluated patients with 5 years of post-operative follow-up and found that worse hip status is associated with hyperlordosis (>60 degrees) in non-ambulatory patients with cerebral palsy and scoliosis.

**Identification of selection criteria for fusing short of the pelvis in Cerebral Palsy Scoliosis:** Dr. Paul Sponseller found that children with pelvic obliquity <16 degrees, GMFCS of 4 or less without the presence of a subluxed hip, and with Thoracic kyphosis of >38 degrees may be ideal candidates for sparing the pelvis during posterior spinal fusion.

**Performing a Definitive Fusion for Scoliosis in Juvenile Cerebral Palsy (CP) Patients is Good Long-term Surgical Option:** Dr. Burt Yaszay found that a definitive fusion is a viable young patients (ages 8-10 years) with scoliosis, and achieves a good correction and remains stable at 5 years post-operatively.



Paul Sponseller, MD



Cerebral Palsy X-Ray



# IDIOPATHIC SCOLIOSIS STUDY

## A PROSPECTIVE DATABASE REGISTRY STUDY

We are extremely grateful for the long-standing support from the primary sponsor of this research effort, **DePuy Synthes Spine, Inc.** In addition, we are thankful for the support from adjunct sponsors of this study: **NuVasive and Stryker/K2M, Inc.**

**Dr. Peter Newton** remains at the helm of this study as the primary investigator. This database registry is the largest, highest quality, comprehensive, longitudinal series of operative outcomes in Idiopathic Scoliosis.



# IDIOPATHIC SCOLIOSIS

## RESEARCH DISCOVERIES IN 2019

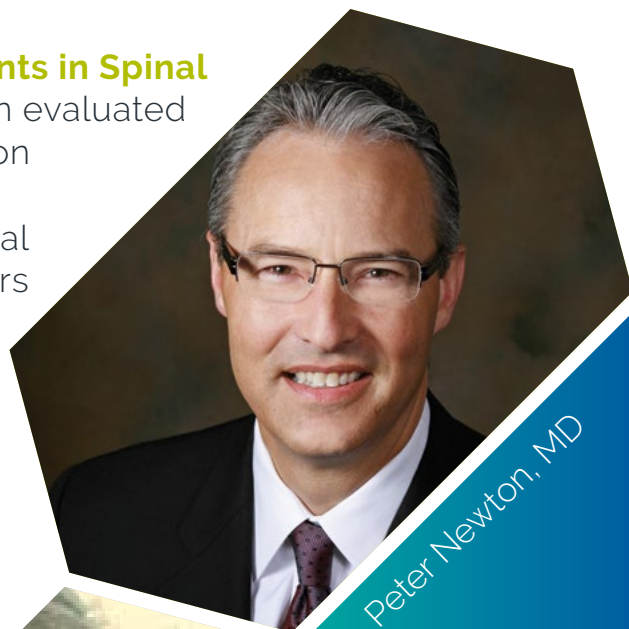
*Research findings presented at Scoliosis Research Society Annual Meeting*

**Residual Curve and Truncal Shift Impact Patient Satisfaction after Surgery for Idiopathic Scoliosis:** Dr. Amit Jain evaluated over 1200 patients with Idiopathic Scoliosis and found that dissatisfaction, as reported through a health related quality of life questionnaire at 2 years post-operatively, is associated with a residual trunk shift and major curve deformity.

**The Ultimate Patient Reported Outcome Tool:** Dr. Baron Lonner unveiled his newly developed, patient-specific outcomes assessment tool called the Patient Generated Index (PGI). He tested this new tool with 45 patients and their parents and found that IS patients and their parents reported different concerns and decision regret regarding surgical treatment. The PGI provides unique insight into patient and parental views toward the disease and treatment.

**The Benefits of Sparing Lumbar Motion Segments in Spinal Fusion for Idiopathic Scoliosis:** Dr. Peter Newton evaluated over 150 patients and found sparing lumbar motion segments in surgery for major thoracic idiopathic scoliosis has clinically significant benefits on spinal motion and health-related quality of life at 10 years postoperatively.

**Sagittal Cervical Alignment After Posterior Spinal Fusion for Idiopathic Scoliosis:** Dr. Josh Pahys sought to understand the malalignment of the cervical spine and found in 48 patients with cervical kyphosis initially present after posterior spinal fusion for idiopathic scoliosis, this malalignment persisted in nearly all patients (97%) at five-year follow-up.

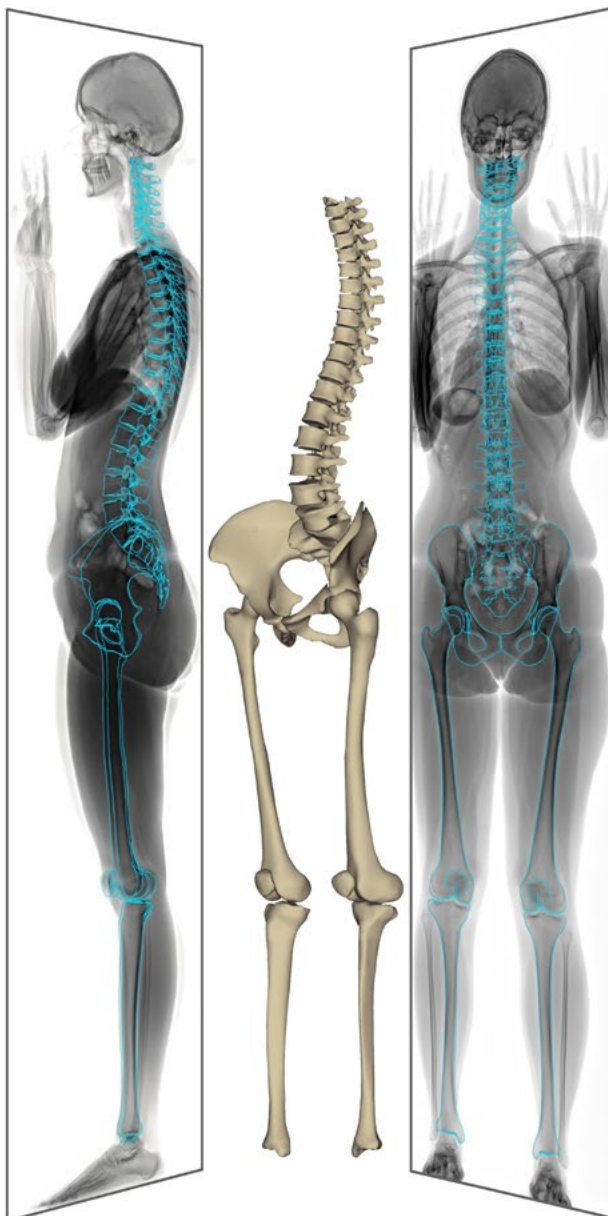


Peter Newton, MD



# FISCAL YEAR 2019 REVENUE & SUPPORT

INDUSTRY RESEARCH  
STUDY SPONSORS,  
SPECIAL EVENT SPONSORS,  
**DONORS** & ALL INCOME:



**78%**

INDUSTRY/SOCIETY  
RESEARCH GRANTS

**10%**

CHARITABLE  
DONATIONS

**4%**

SPONSORSHIPS

**4%**

INVESTMENT INTEREST

**3%**

DATABASE

**1%**

SPECIAL EVENTS/  
EDUCATION

# FINANCIAL REPORT

## FUNCTIONAL EXPENSES

89%

### EIGHTY-NINE

PERCENT OF EVERY  
DOLLAR WE RECEIVE  
GOES DIRECTLY TO  
**OUR MISSION** AND  
**OUR COMMITMENT**

44%

RESEARCH AND  
STUDY EXPENSE

39%

RESEARCH & EDUCATION  
COORDINATION

15%

MANAGEMENT &  
GENERAL

2%

FUNDRAISING  
EXPENSES



Countless children's lives  
across the globe have  
been positively impacted  
by the work of The  
**Harms Study Group** and  
**Setting Scoliosis Straight**



**DePuy Synthes**

COMPANIES OF *Johnson & Johnson*

**stryker**<sup>®</sup>

**Medtronic**

**EOS**  
imaging

**DOUBLE DIAMOND:**  
**\$1,000,000+**

**DIAMOND:**  
**\$500,000 - \$999,999**

DePuy Spine, Inc.

**PLATINUM:**  
**\$250,000 - \$499,999**

Stryker

**GOLD:**  
**\$100,000 - \$249,999**

EOS Imaging Inc.

Medtronic Spinal

**SILVER:**  
**\$10,000 - \$99,999**

Nuvasive  
CHU Sainte-Justine  
Medicrea

**BRONZE:**  
**\$5,000 - \$9,999**

Food and Drug Administration  
Globus Medical  
National Scoliosis Center -  
Baltimore  
Scoliosis Research Society

**COPPER:**  
**\$1 - \$4,999**

Abbott Laboratories -  
Employee Match  
Ability Prosthethics & Orthotics, Inc  
CD Denison Orthopaedic  
Appliance Corp  
Globus  
Green Sun Medical LLC  
Scheuermann's Disease  
Foundation

## WITH APPRECIATION

**PATRON:**  
**\$25,000 - \$49,999**

Goldfarb, Jeffrey and Stacey  
Johnson & Johnson -  
Donate a Photo  
Johnson & Johnson PAC Match -  
Employee Donation  
Lonner, Baron, MD  
Newton, Cathy & Peter, MD  
Welch, Mr. & Mrs. William

**FELLOW:**  
**\$10,000 - \$24,999**

Arthur M James Family Foundation  
Lenke, Beth and Larry, MD  
Ruvo, Larry and Camille  
Sponseller Paul, MD

**ADVOCATE:**  
**\$5,000 - \$9,999**

Barbara Havenick & Jennifer  
Bielawski Family  
Cahill Megan and Patrick, MD  
Errico, Thomas J., MD  
Flynn, Mr & Mrs. John, MD  
Hedequist, Daniel, MD  
Xenos, Faith Read

**AFFILIATE:**  
**\$1,000 - \$4,999**

Akbrarnia, Behrooz and Nasrin  
Bachmann, Keith, MD  
Betz, Randal and Betsey, MD  
Buckland, Aaron, MD  
Clements, David, MD  
Erickson, Mark, MD  
Gabos, Peter, MD

Garg, Sumeet, MD  
George, Stephen, MD  
Hwang, Steven, MD  
Irvine, Kathleen E.,  
Jain, Amit, MD  
Jamieson, Bo and Linda  
Johnson & Johnson/Depuy  
Synthes - Employee Fundraiser  
Kelly, Michael, MD  
Larson, Noelle, MD  
Marks, Eddie & Michelle  
Nemours Employee Fundraiser -  
Scoliosis Awareness  
Rosenberg, William  
Samdani, Amer, MD  
Shah, Suken, MD  
Shufflebarger, Harry, MD  
Smole, Mr. and Mrs. Kevin  
Stikeleather, Luke  
Stone, Robert  
Sturm, Peter  
Vasicek Foundation

**FRIEND:****\$500 - \$999**

Anonymous  
 Bieker, Arlene  
 Crawford, Alvin H, MD  
 Detray, Sylvia and George  
 Fletcher, Nicholas, MD  
 German Club Alumni  
 Foundation  
 Hardesty, Lindsay  
 Koehler, Michelle  
 Lexer, Todd  
 Miller, Jane  
 Miller, Warren and Jade  
 Milne, Colleen  
 Moshirfar, Dr. Ali  
 Mountain, Doug  
 Mulcahy, John  
 Padilla, Jennifer and Milton  
 Pahys, Josh, MD  
 Rice, Brian  
 Rip Yuki Giving Fund  
 Somers Charitable Fund  
 Stokes, Jessica  
 Sucato, Dan  
 Sylvia, Ross  
 Constantelos, Joanna

**SUPPORTER:****\$1 - \$499**

Airbnb Employees  
 Amawi-Serhan, Amirah  
 Anderson, Jamie  
 Andrie, Matthew J.  
 Bacci, Diana G.  
 Barret, Edward  
 Bealka, David  
 Beard, Shawanna  
 Begent, Jay Hall  
 Belanger, Rachael  
 Belna, Sara  
 Bernardo, Heather  
 Bizzari, Melissa T.  
 Bloom, Clara  
 Boyington, Jody  
 Bray, Sarah  
 Brushart, Sandra  
 Burston, Liv  
 Camara, Lindsey  
 Cannon, Heather M.  
 Coil, Laurel  
 Cotone, Joseph  
 Creasy, Kenneth E.  
 Crispo, Jeffrey M.  
 Crowell, Melissa

Dalupang, Mary  
 Diana, CT  
 Daniels, Akilah T.  
 De Bellis, Cassandra  
 Denis, Cal  
 Desnoyer, Jessica  
 Donahue, James R.  
 Dubroff, Susan and Rich  
 Emelian, Shawn  
 Feeney, Jaime  
 Feng, Hoshi and Frank  
 Ferris, Sandra  
 Ficke, James  
 Fletcher, Donald  
 Flood, Ann  
 Flunker, Kristie  
 Flynt, Jenna  
 Foley, Jason  
 Fought, Melissa  
 Frank, Stacey  
 Gallina, Tom  
 Gerber, David  
 Gesuelli, Kayla  
 Gesueli, Victoria  
 Glassman, Mark  
 Godin, Michelle  
 Gohel, Shivani and Sankar,  
 Wudbhav  
 Gorhan, Michael C.  
 Greeaney, Allison  
 Greenberg, Robert  
 Gruwell, Shawna  
 Halsey, Matthew  
 Hammond, Saibr  
 Haridas, Divya  
 Harwood, Kristen  
 Heiss, Jared  
 Heiss-Tiplady, Lori  
 Hostetter Strent  
 Jackson, Carl M.  
 Jenks, Perry  
 Joffe, Kelly  
 Jong, Daphne  
 Juskowitz, Ruth  
 Kearny, Mary G. F.  
 Keller, Barbara  
 Keniston, Cynthia R.  
 Krichman, Lauren  
 Kushkin, Seth  
 Kutilek, Nancy  
 Lee, Kevin  
 Lien, Peiting  
 Light, Andrea  
 Lott, Timothy  
 Luu, Phat T.  
 Ly, Harvey  
 Malone, John Daniel

Mangold, Lucas  
 Marchese, Jeffrey  
 McClaugherty, Ana Cecilia  
 Merrill, Michelle  
 Messier, Christina  
 Mhilli, Erseida  
 Miller, Clayton E.  
 Mountain, Doug  
 Myette, Brian  
 Nasr, Amine  
 Neiss, Mr. and Mrs. Melvin  
 Niese, Justin M.  
 Niethammer, Deborah  
 One Hope  
 Paik, Marilyn  
 Paiva, James A.  
 Patidar, Leena  
 Patschull, Cynthia  
 Pawlowski, Nathan  
 Petsas, Laurel  
 Putnam, Deanna  
 Quintana, Lilliana  
 Rifai, Bassel  
 Rigsby, Chris  
 Runco, Thomas J.  
 Sanders, Wiley  
 Sankar, Wudbhav, MD  
 Serhan, Hassan  
 Serwaa, Whitney  
 Sicilani, Lisa  
 Sinder, Daniel  
 Smith, Keith  
 Smith, Sally  
 Smole, Kevin  
 Smole, Kevin and Barbara  
 Spranger, John G.  
 Stein, Nathan J.  
 Stillman, Judie  
 Talis, Joanna  
 Teehan, Brennan  
 Teehan, Lindsay  
 Thatte, Suhas  
 Tokarz, Carol I.  
 Torres, Jerry  
 Touchton, Jody  
 Tuminello, Nicholas J.  
 Turner-Bare, Karen  
 Way, Naomi  
 Waites, Julie Gunter  
 Webster, Mr. and Mrs. James  
 Wencis, Craig R.  
 Werz, Florian  
 Wieczorek, Beth  
 Will, Jana  
 Williams, Genine  
 Wright, Sheri

# SHARE YOUR STORY!

Each patient with a spine deformity has a unique story to tell. Setting Scoliosis Straight has shared over **50 inspirational stories** from patients who have had spinal treatment and wish to give hope to others.



## WRITE

your personal experience and journey with scoliosis.



## SEND

us your story via email along with several pictures of yourself.



## SHARE

your personal page on our website with friends and family.

Visit our website at  
**[www.settingscoliosisstraight.org](http://www.settingscoliosisstraight.org)**  
to read our patient stories.



# PATIENT STORY

## IZZY MARZANO

My name is Izzy & I'm 14 years old. Three and a half years ago, at my annual school physical, my doctor noticed I had a curve in my spine when I bent over. She referred me to Rady Children's Hospital where I met with Peter Newton, MD, a Pediatric Spine Surgeon. He told me I had Adolescent Idiopathic Scoliosis also known as AIS and a double curve of my spine. Dr. Newton described the degree of my curves as 20 degrees thoracic and 40 degrees thoracolumbar. He said I had two options. The first was bracing my spine. The second option was fusion surgery. When I heard the options, I chose bracing. I wore my brace religiously for 22 hours every day until my curve slowly reduced and now I'm scoliosis and brace free!



To read Izzy's full story,  
visit our website at:

[www.settingscoliosisstraight.org](http://www.settingscoliosisstraight.org)

Izzy Marzano & her father



# 2019 HSG ACCOMPLISHMENTS



## NEW SRS PRESIDENT

**Peter Newton, MD** handing over the SRS Presidency to HSG member **Paul Sponseller, MD** at the 2019 Scoliosis Research Society's Annual Meeting in Montreal, Canada.

## SURGEON PERFORMANCE PROGRAM

The Setting Scoliosis Straight **Surgeon Performance Program (SPP)** Quality Improvement Initiative is now featured in US News & World Report's 2019 survey for ranking pediatric hospitals! We are honored for this recognition as we continuously strive to enhance our QI effort and promote optimal patient care on a global scale.



## MENTORING EVENT

**Dr. Suken Shah** and his team at the the Nemours Spine and Scoliosis Center held a hospital wide 2019 Scoliosis Awareness Day and raised funds for scoliosis research and patient advocacy. The proceeds of this effort were donated to Setting Scoliosis Straight!



# SURGEON PERFORMANCE PROGRAM

The Setting Scoliosis Straight **Surgeon Performance Program** is a quality improvement initiative designed for orthopedic surgeons to help optimize performance and improve patient outcomes in the treatment of Idiopathic Scoliosis, Neuromuscular Scoliosis & Pediatric Spondylolisthesis. Through participation in this quality improvement registry and routine dashboard reporting, surgeons can evaluate their performances and advance patient care.



The Surgeon Performance Program has been approved by the **American Board of Orthopaedic Surgery (ABOS) Maintenance of Certification (MOC)** Committee as an alternate choice for earning self-assessment examination (SAE) credits for the Board's MOC process.

The program is featured in **US News & World Report's** survey for ranking pediatric hospitals! We are honored for this recognition as we continuously strive to enhance our quality improvement efforts and promote optimal patient care on a global scale.

✓ Track patient/surgeon variables to evaluate and improve treatment processes and patient outcomes.

✓ Utilize comparative practice data in dashboard reports, which highlight where a surgeon 'ranks' relative to his or her peers.

✓ Identify best practices through shared learning and self-evaluation, and use data to guide a personalized quality improvement journey!

## OR Time Summary



Sample SPP Dashboard Report: Operating Room (OR) Time

Visit our website for more information

[www.registries.settingscoliosisstraight.org](http://www.registries.settingscoliosisstraight.org)

This program would not be possible without the generous support from Medtronic and NuVasive!

Medtronic



# THERE ARE MANY WAYS TO GIVE

Whether it is money or time, there are many ways to give to the **Setting Scoliosis Straight Foundation** to help us support discoveries and advance techniques in the treatment of spinal deformities in children and adolescents worldwide.



**DONATE  
TODAY**



**MONTHLY  
GIVING**



**MATCHING  
GIFTS**



**DONATE  
A CAR**



## **JOIN A PEER-TO-PEER FUNDRAISER**

Peer to Peer Fundraising is a social/team/personal fundraising method in which our supporters fundraise on behalf of the SSSF.



## **START YOUR OWN FUNDRAISER**

Organize an event such as a sporting event or tournaments, 5K Walk/Run, Fashion Show and Dance-off to raise money for the SSSF. To get started, fill out the application below.





The shopping sites, apps and rewards programs below offer easy ways to help Setting Scoliosis Straight.



Visit our website today for more information!

[www.settingscoliosisstraight.org](http://www.settingscoliosisstraight.org)



# SSSF INFRASTRUCTURE

Our staff is a reflection of the diverse patient population we serve; several of whom have been with the organization since its inception – nearly twenty-five years!



**MICHELLE MARKS**

Executive/Research Director



**MATY PETCHARAPORN**

Research/Database Manager



**HARVEY LY**

Research/ Development/ Webmaster



**TRACEY BASTROM**

Statistician



**JON MARIE BASEL**

Contracts/ Finance Manager



**MARY DALUPANG**

SPP Database Manager



**KERRY BETANCOURT**

Research Assistant



**HEATHER GUERRESO**

Research Assistant



**MONICA LEE**

SPP QI Manager



**MELODY DICK**

Research Assistant



**JAMIE ANDERSON**

Development Manager



**ADAM BOND**

Research Assistant



**HEIDI FERNANDEZ**

Research Assistant



**ALAN SANCHEZ**

Administrative Assistant

# SCOLIOSIS HANDBOOK & FAQ VIDEOS

The Setting Scoliosis Straight Foundation is proud to share our multi-chapter scoliosis video handbook with you and your family. The core purpose for creating this video is to educate and support scoliosis patients, their families, friends and the entire scoliosis community. Twenty-five years of research from the Harms Study Group, have been used to create this scoliosis video focused on evidence based information.

## TOPICS INCLUDE:

- ✓ What is Scoliosis?
- ✓ How to Detect Scoliosis
- ✓ What is Scoliosis Bracing?
- ✓ What is Scoliosis Surgery?
- ✓ What to Expect Before and After Surgery
- ✓ Life After Scoliosis Surgery
- ✓ Future Pregnancy



We have also created multiple FAQ videos to provide additional information to newly diagnosed patients with evidence-based information from the Harms Study Group surgeon members around the country.

## TOPICS INCLUDES:

- ✓ Scheuermann's Kyphosis
- ✓ Body Casting
- ✓ Halo Traction
- ✓ Tethering
- ✓ Schroth Method
- ✓ Pregnancy After Scoliosis



Visit our website to  
view all our videos:

[www.settingscoliosisstraight.org](http://www.settingscoliosisstraight.org)

## IN LOVING MEMORY OF KENT RUSSELL

We were truly blessed to have known and worked with Kent from **FatBox Inc.** over the past 2 years. These videos wouldn't have been possible without the help from Kent and his team. Our deepest and most sincere condolences go out to Kent's family and loved ones.





## PATIENT STORY

# EMILY PAINTER

The summer of 2016, I had just graduated from elementary school and was about to start grade nine at a new school with new people. Growing up I had always gone to a separate Catholic school and I was now moving to a public school. I was excited but nervous to start this new chapter as any other 14-year-old is. One night my back was sore so I asked my mom to rub it, I bent over a chair and I heard her gasp, asking what was wrong with my mom kept asking me to straighten my back out and I kept responding that I was. Instantly my mom started freaking out saying she was bringing me to Sick Kids the next day. As I've grown up in and out of hospitals, I immediately declined to tell her I just wouldn't go, and she was overreacting. As we kept arguing about it, we settled on visiting the local hospital the next day to get an x-ray. We got up and went and I was sent for my first of three x-rays that day. After the first one, I remember sitting in the room while being so angry at my mom for bringing me there, I was convinced she was overreacting, and nothing was wrong. The doctor came in within 15 minutes of the scan saying they needed to take some more photos and run over the images. Me being confused I followed the doctor where we proceed to have two other scans done. Now, I was nervous. I knew something had to be wrong if they were asking me to have multiple scans done. 20 minutes later we were called out by the doctor to review the x-rays. Staring back at me as my throat ran dry and my eyes started to well up, I saw the x-rays reflect the curve of my spine, the reason behind my reaction was the doctor saying that the only option I had was surgery. I was in disbelief.



To read Emily's full story,  
visit our website at:

# 2020 ANNUAL EVENTS

**DUE TO CONCERNS SURROUNDING THE CORONAVIRUS (COVID-19) OUR 2020 EVENTS ARE GOING VIRTUAL.**

**Power Over Scoliosis**, a **FREE** and comprehensive program created to educate scoliosis patients and their families on proven (and unproven) scoliosis treatments will be an **Online Webinar** course this year. This course will be FREE and anyone can join!

We are excited to keep the momentum, publicity, and energy of our 2020 fundraiser without a live in-person event by holding a **'non-gala'** (*online fundraiser*) this year.

This fundraising effort is critical to raise funds for scoliosis research & to improve patient care worldwide.



For more information, visit our website at:

[www.settingscoliosisstraight.org](http://www.settingscoliosisstraight.org)

## POWER OVER SCOLIOSIS

### ONLINE WEBINARS

**MAY 30, 2020**

Evidence-based info and Q&A with surgeons.

**JUNE 20, 2020**

Peer-to-Peer patient info sharing and Q&A with patients and surgeon moderator.

*\*Dates and content subject to change*

## AHEAD OF THE CURVE NON-GALA

### What is a Non-Gala?

The non-gala is a virtual fundraiser that gives you the opportunity to make a charitable tax deductible donation without leaving the comfort of your own home.

Our in-person POS and AOTC events will be back in NYC in 2021.

# FOLLOW US



## CONTACT US



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Fax: 619-410-1433



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