



Supporting Discoveries in Spinal Deformities



2020

Annual Report

HSG
HARMS STUDY GROUP
Pioneering Research in Spinal Deformities



WWW.SETTINGSCOLIOSISSTRAIGHT.ORG

Message From The President



Dear **Friends,**

We are proud to share with you the accomplishments of Setting Scoliosis Straight during the most challenging year we have all faced. Despite the COVID-19 pandemic, the patients we serve continue to need our expertise. Scoliosis progression knows nothing about social distancing... We certainly had to pivot several times this past year, and in the end many of our goals were realized. New discoveries that change lives continue whether we meet virtually or in person. The same committed physicians, researchers, staff and volunteers got the work done, thank you all.

Our online educational content for patients continues to grow and we have partnered with the Food and Drug Administration to gather input from our patients on what's important to them as they navigate their journey in life with scoliosis. We appreciate the partnership and look forward to bringing those additional research studies and additional collaborations to you all soon.

Thank you again for your ongoing and continued support of our mission.

Peter Newton, MD

President, Setting Scoliosis Straight

Dear Scoliosis Family,

In reflecting on the persistent state of chaos that encompassed 2020, I am filled with pride and gratitude for the unwavering resilience of our team and research sites. Their ability to quickly pivot to maintain research data collection enabled the successful continuation of our multicenter studies despite obstacles presented by the pandemic. Sadly, we were unable to celebrate the 25th anniversary of the Harms Study Group in New York as scheduled in 2020. However, we experienced many positive developments, including the launch of our Non-Fusion research, and new collaborations with surgeons, industry partners, and the FDA.



Michelle Marks, PT, MA

Executive Director,
Setting Scoliosis Straight

Our Patient Education efforts shifted from in-person to virtual settings and our educational video content expanded significantly. We remain committed to improving the lives of patients with scoliosis and look forward to the next 25 years!

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Supporting Discoveries in Spinal Deformities

THE NON PROFIT FOUNDATION

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. The **Foundation** focuses on fundraising, awareness, patient education and improving quality in care.

A circular portrait of Emma Sayar, a young woman with long brown hair and bangs, smiling. The portrait is partially overlaid by a dark blue circle containing her name.

EMMA
SAYAR

“

Don't be scared.. I was scared too, but everything turned out fine!”

Emmatisse was 9 years old when she discovered she had scoliosis. She was diagnosed with a 51 degree thoracic curve. Emmatisse had her scoliosis treated with Vertebral Body Tethering (VBT) to correct her curve. Although she had a few setbacks with her treatment, she keeps a smile on her face and remains focused on creating awareness of scoliosis and raising funds for scoliosis research.

Emmatisse recently held the largest single person fundraiser to benefit Setting Scoliosis Straight. She raised over \$1,900.

We recently met with Emmatisse to discuss her treatment. Visit our website to read more.

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.



SUPPORT

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.

OUR BOARD OF DIRECTORS

Members of Setting Scoliosis Straight's board of directors are all uniquely connected to spinal deformities. This diverse group of individuals, volunteer their time, expertise, and energy, to ensure the foundation is successful in fulfilling its mission.



PETER NEWTON, MD

PRESIDENT & CHAIRMAN



DAVID CLEMENTS, MD

VICE PRESIDENT



MICHELLE MARKS, PT, MA

SECRETARY



ROBERT STONE, CPA

TREASURER

MESSAGE FROM A BOARD MEMBER

“

In my 20 years as an industry partner to the foundation, I have always been incredibly moved hearing stories from patients and their families and the impact surgery had on their lives. I too had a life changing orthopedic procedure when I was a child, and to now be a part of the foundation is an incredible honor. I am truly humbled to be serving on the board to help continue the great work of advancing patient care.”

- Ross Sylvia



RANDY BETZ, MD



THOMAS ERRICO, MD



STACEY GOLDFARB, Esq.



LAWRENCE LENKE, MD



BARON LONNER, MD



AMER SAMDANI, MD



KEVIN SAYAR, Esq.



SUKEN SHAH, MD



HARRY
SHUFFLEBARGER, MD



FIROZ MIYANJI, MD



BO JAMIESON



ROSS SYLVIA



2019 CUTTING
EDGE MEETING
MIAMI, FLORIDA

NEW AMBASSADOR



DANCE FOR A CAUSE
RAISED OVER \$650!



Alyssa Holtrust
Scoliosis Ambassador

We are excited to introduce our new Scoliosis Ambassador, **Alyssa Holtrust**. Alyssa was diagnosed with scoliosis when she was 15 years old. But that didn't stop her from dancing!

Alyssa had reached out to SSS to start a fundraiser. She has done an amazing job organizing a successful dance class called, "**Dance For a Cause**" to fundraise for scoliosis research.

We cannot thank her enough for her amazing support!

2020 FUNDRAISERS

SPECIAL THANKS TO EVERYONE WHO STARTED A 2020 FUNDRAISER TO HELP SETTING SCOLIOSIS STRAIGHT FOUNDATION!

SCAN QR CODE

to learn how to start your own fundraiser.



| | |
|-------------------------|----------------|
| Live Fundraisers | Raised \$650 |
| Peer 2 Peer Fundraisers | Raised \$2,241 |
| Facebook Fundraisers | Raised \$3,384 |
| GoFundMe | Raised \$1,910 |

HOW TO BECOME A SCOLIOSIS AMBASSADOR

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.

HOW IT WORKS



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to visit our
Ambassador page to
get started today.



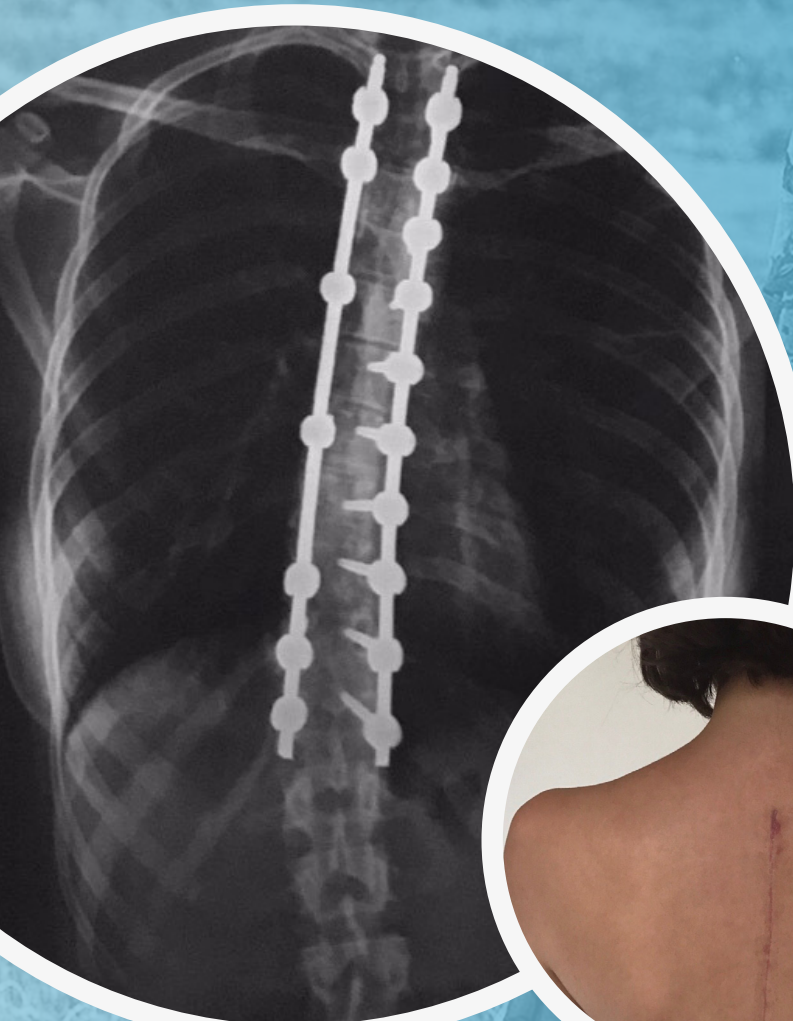
There are many more ways you can get involved with Setting Scoliosis Straight. Visit our website today for more information.

www.settingscoliosisstraight.org

CHARLEE FRASER



Charlee Fraser is an Indigenous Australian international supermodel that has scoliosis. Charlee has walked the catwalk for some of the most famous designers and graced the covers of Vogue, Harper's Bazaar, Marie Claire and many more. She has represented and starred in several major designer cosmetic, eyewear and designer clothing ad campaigns.



SCAN QR CODE
to read Charlee's full
story and interview.

How old were you when you were diagnosed with Adolescent Idiopathic Scoliosis?

I recognized my scoliosis around the age of 14 and was diagnosed shortly after by my family doctor. At the time of diagnosis, my doctor did not suggest a brace nor surgery but rather exercise such as swimming and yoga to help as a preventative.

What were your emotions?

Pre-surgery I was excited! Upon diagnosis, I was not presented with any possible avenues such as a brace or correctional surgery and was delighted by the idea of having a choice. Post-surgery I was determined to resume life and lead my recovery with a strong and positive mind set. I honestly believe this helped me through my experience. I was in very little pain and returned to work after only four weeks.

Do you have any advice for others diagnosed with scoliosis?

Stay positive! It is a little daunting at first but understand that you have options and you are most certainly not alone. This is a part of who you are and a part of your journey. Take time to accept how it makes you feel and look for that silver lining. This life chose you because you are one of the few strong enough to conquer; so, share your story with pride and notice how others flock to see you shine.

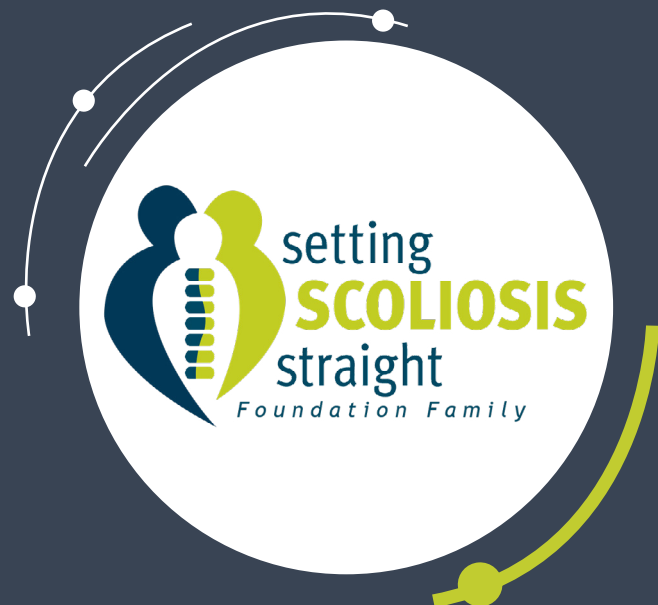
What is your mission now (to give back, spread awareness, etc.)?

My mission now is to not only financially support research into spinal fusion surgery (whenever I can) but encourage others to work on positivity and optimism. I do this by sharing my story through multiple social media platforms, attending/speaking at events and webinars, and working alongside the Setting Scoliosis Straight Foundation in creating a comfortable space for people to learn and ask questions.

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!



Contact us at info@ssshsg.org
if you would like to be part of our
Foundation Family

NEW SPINAL FUSION BOOKLET



Four Scoliosis Patients

Setting Scoliosis Straight recently connected with four young scoliosis patients that created a pamphlet for scoliosis patients that are about to undergo Spinal Fusion surgery. The pamphlet was developed to address how to prepare for surgery and what to expect after surgery to help make the journey through spinal fusion surgery a little bit easier on the patients and their families.

The girls, Amanda, Talia, Sydney, and Chloe, who range in age from middle school to high school, have all undergone spinal fusion surgery to correct scoliosis. The girls met through their doctor who connected them with each other so they could share their experiences. Once the girls got to talking, they came up with the idea to gather information from other patients and create a pamphlet that helps others who are about to have surgery.

“*Our surgeries affected us physically, but they also had a huge impact on our families, our school life, and our daily activities. Although it may seem like a long, terrifying process, we all feel that surgery had a positive impact on both our physical health and our self-confidence.*”

SCAN QR CODE
to learn how you can
download this free
booklet.



PATIENT EDUCATION

■ SSS HOSTED FOUR WEBINARS IN 2020

Setting Scoliosis Straight has hosted an in-patient education course, called **POWER OVER SCOLIOSIS** in various US cities since 2016.

Due to **COVID-19**, we were forced to cancel this event in 2020. This pandemic has challenged us in many ways, but that didn't stop us from educating patients and their families.

Since we all have been spending a lot of time at home this year, we decided to hold several webinars to educate and provide expert insight to patients and their families. Some of these webinars included patients sharing their experiences and offering advice to newly diagnosed patients.

A big Thank You to all of the doctors and patients that participated.

We look forward to holding more webinars in 2021.

Go to page 37 for more information



SCAN QR CODE

to watch all of our
webinar recordings.

2020 PATIENT EDUCATION WEBINARS HELD:

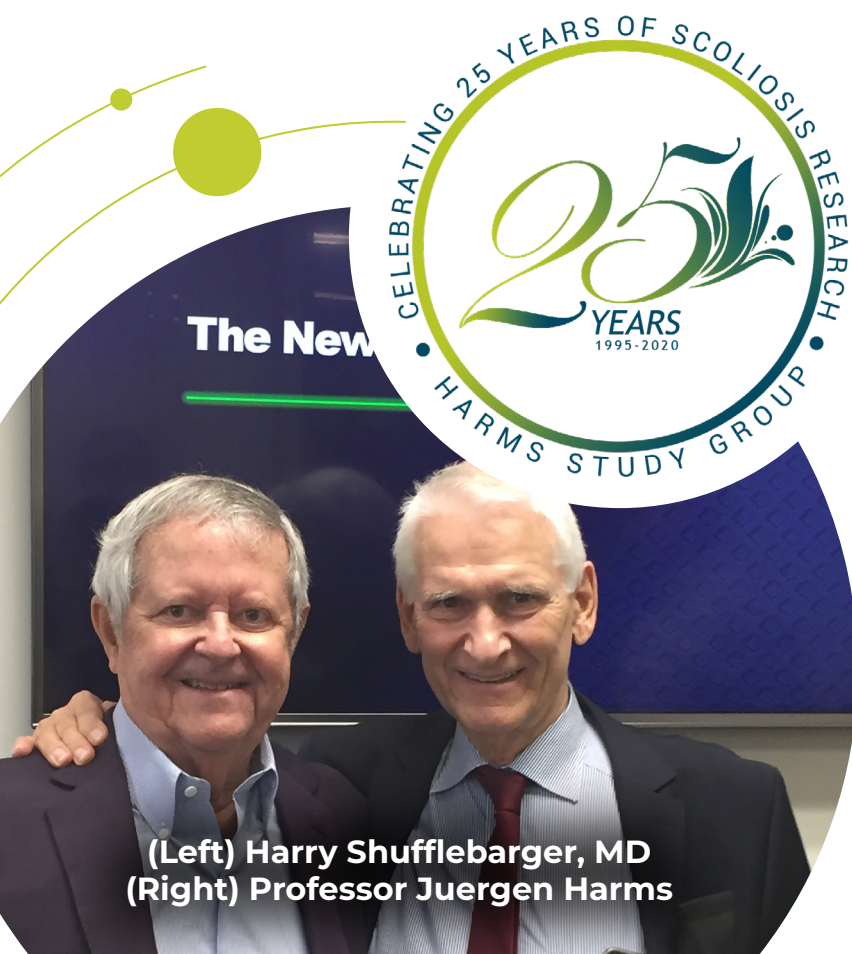
| | |
|------------------|----------------------|
| June 18, 2020 | COVID-19 & Scoliosis |
| July 23, 2020 | Patients 2 Patients |
| October 8, 2020 | Power Over Scoliosis |
| October 29, 2020 | Patients 2 Patients |



THE RESEARCH GROUP

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

This **Research 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.

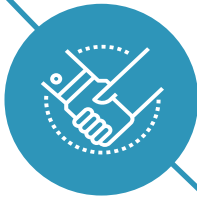


“*Congratulations to HSG on their Silver anniversary of their founding. The accomplishments are amazing. More amazing accomplishments are on the horizon, given the involvement with the non-fusion studies just beginning. Only the best wishes for the future of HSG.*”

*- Harry
Shufflebarger, MD*

(Left) Harry Shufflebarger, MD
(Right) Professor Juergen Harms

WHAT WE DO



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 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 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

HSG MEMBERS

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Vancouver, Canada



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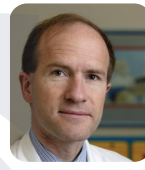
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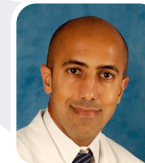
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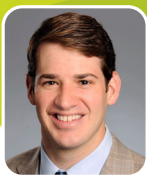
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Hospital Miami, Florida



Stephen Goerge, MD
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Hospital Miami, Florida

2020 SCIENTIFIC PRESENTATIONS



As most scientific annual meetings were shifted to Virtual Events due to COVID-19, HSG scientific presentations were reduced this year.

International Meeting on Advanced Spine Techniques (IMAST), held virtually July 17-19, 2020:

- **2 Poster Presentations**
- **2 Podium Presentations**

Scoliosis Research Society (SRS), held virtually September 9-13, 2020:

- **6 Poster Presentations**
- **14 Podium Presentations**

1. **Newton PO** et al. Prospective 10-year follow-up assessment of spinal fusions for thoracic AIS: radiographic and clinical outcomes *Spine* 2020 Feb;8(1):57-66
2. **Fletcher ND**, et al. Fusions Ending at the Thoracolumbar Junction in Adolescent Idiopathic Scoliosis: Comparison of Lower Instrumented Vertebrae. *Spine Deform.* 2020 Feb. 5.
3. **Buckland A.**, et al. Residual lumbar hyperlordosis is associated with worsened hip status 5 years after cerebral palsy scoliosis correction. *The Spine Journal.* 19. S152. 10.1016/j.spinee.2019.05.329.
4. **Lonner, B.**, et al. Is Anterior Release Obsolete or Does it Play a Role in Contemporary Adolescent Idiopathic Scoliosis Surgery? A Matched Pairs Analysis. *J Pediatr Orthop.* 2020 Mar;40(3):e161-e165.
5. Lindgren A., **Newton PO**, et al. Quality Improvement in Post-Operative Opioid and Benzodiazepine Regimen in Adolescent Patients after Posterior Spinal Fusion. *Spine Def A.orm.* 2020 Jan 8.
6. Eguia F., **Sponseller P.**, Of Major Complication Types, Only Deep Infections after Spinal Fusion are Associated with Worse Health-Related Outcomes in Children with Cerebral Palsy. *Spine2020*; Epub ahead of print, Mar 6.
7. Baldwin KD, **Cahill PJ.** BMI change following spinal fusion for neuromuscular scoliosis surgery. *Spine Deform* 2020 May 11.

& PUBLICATIONS

8. Ohashi M., **Newton PO.** The Benefits of Sparing Lumbar Motion Segments in Spinal Fusion for Adolescent Idiopathic Scoliosis Are Evident at 10 Years Postoperatively. *Spine* 2020 Jun 1;45(11):755-763.
9. Vivas AC., **Hwang SW.**, Early and Late Hospital Readmissions After Spine Deformity Surgery in Children with Cerebral Palsy. *Spine Deformity* 2020 Jun;8(3):507-516.
10. LaValva S., **Cahill P.**, Prolonged Postoperative Intubation After Spinal Fusion in Cerebral Palsy: Are There Modifiable Risk Factors and Associated Consequences? *J Pediatr Orthop* 2020 Sep;40(8):431-437.
11. Anari J, **Flynn J.** The impact of posterior spinal fusion (PSF) on coronal balance in adolescent idiopathic scoliosis (AIS): a new classification and trends in the postoperative period. *J Pediatr Orthop* 2020 Oct;40(9):e788-e793.
12. Segal D., **Fletcher ND.**, Fusions Ending Above The Sagittal Stable Vertebrae in Adolescent Idiopathic Scoliosis: Does it Matter? *Spine Deform.* 2020 Oct;8(5):983-989.
13. **Lonner B.**, The Patient Generated Index and Decision Regret In Adolescent Idiopathic Scoliosis. *Spine Deform.* 2020 Dec;8(6):1231-1238.
14. Beauchamp E., **Lenke LG.**, Radiographic Results of Selecting the Touched Vertebra as the Lowest Instrumented Vertebra in Lenke Type 1 (Main Thoracic) & Type 2 (Double Thoracic) Curves at a Minimum 5-year Follow-up. *J Bone Joint Surg Am.* 2020 Nov 18;102(22):1966-1973.
15. Bodendorfer BM, **Shah SA.**, Restoration of Thoracic Kyphosis in Adolescent Idiopathic Scoliosis over a Twenty Year Period: Are We Getting Better? *Spine.* 2020 Dec 1;45(23):1625-1633
16. Bauer JM, **Shah SA.**, Comparing short-term AIS postoperative complications between ACS-NSQIP and a surgeon study group. *Spine Deform.* 2020 Dec;8(6):1247-1252.
17. Hughes J., **Yaszay B.**, Long Term Patient Perception Following Surgery for Adolescent Idiopathic Scoliosis if Dissatisfied at 2 Year Followup. *Spine.* 2020 Dec 1.
18. Verhofste B., **Glottzbecker MP.**, Risk Factors for Gastrointestinal Complications after Spinal Fusion in Children with Cerebral Palsy. *Spine Deform* 2020 Nov 17.
19. Kluck D., **Newton PO.**, A 3D Parameter Can Guide Concave Rod Contour for the Correction of Hypokyphosis in Adolescent Idiopathic Scoliosis. *Spine (Phila Pa 1976).* 2020 Oct 1;45(19):E1264-E1271.
20. **Yaszay, B.**, Major complications following surgical correction of spine deformity in 257 patients with cerebral palsy. *Spine deformity*, 1–8. 27 Jul. 2020.
21. Shen K., **Newton PO** Threedimensional analysis of the sagittal profile in surgically treated Lenke 5 curves in adolescent idiopathic scoliosis. *Spine Deform.* 2020 Jul 23.
22. Sikora-Klak, J., **Upasani, V.V.**, Three-dimensional analysis of spinal deformity correction in adolescent idiopathic scoliosis: comparison of two distinct techniques. *Childs Nerv Syst* (2020).
23. Sullivan TB, **Newton PO.** More severe thoracic idiopathic scoliosis is associated with a greater three-dimensional loss of thoracic kyphosis. *Spine Deform.* 2020 Jun 2.
24. Bram JT, **Cahill PJ**, Sinister! The High Pre-op Left Shoulder is Less Likely to be Radiographically Balanced At 2 Years Post-Op. *Spine Deform.* 2020 Nov 17.
25. Ohashi M., **Newton PO.**, Associations between three-dimensional measurements of the spinal deformity and pre-operative SRS-22 scores in patients undergoing surgery for major thoracic adolescent idiopathic scoliosis. *Spine Deform.* 2020 Dec;8(6):1253-1260

CEREBRAL PALSY SCOLIOSIS STUDY

A Prospective Database Registry Study

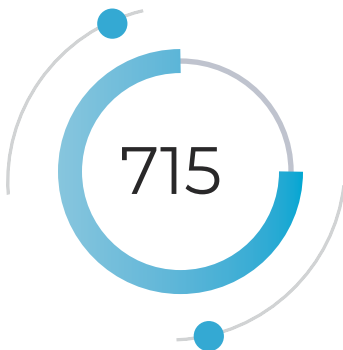
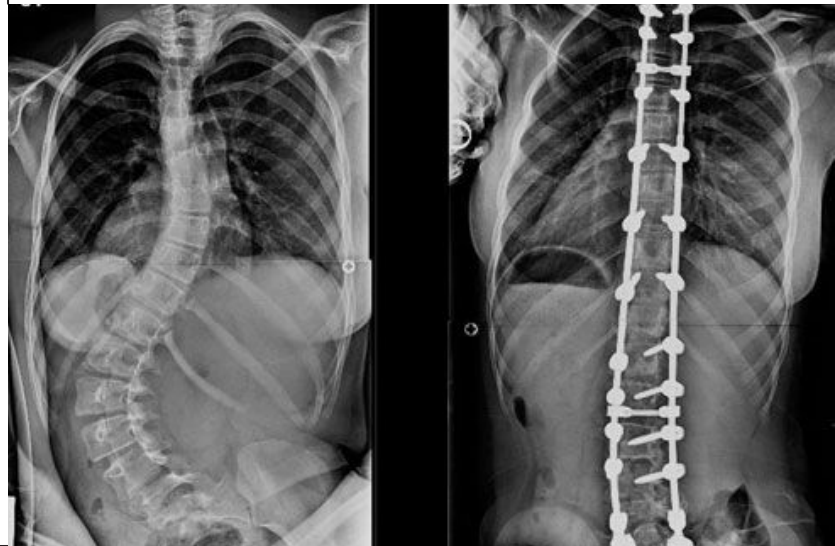


Paul Sponseller, MD
Primary Investigator

stryker[®]

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

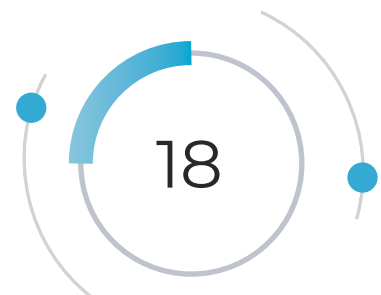
Leading the charge for this study is primary investigator, **Paul Sponseller, MD**, who is the Chief of the Division of Pediatric Orthopaedics at Johns Hopkins Children's Center. Dr. Sponseller has been a member of the Harms Study Group since 2004.



**OPERATIVE PATIENTS
DATA COLLECTED**



**NON-OPERATIVE
PATIENTS DATA
COLLECTED**



**RESEARCH SITES &
HOSPITAL PARTICIPATING**

RESEARCH DISCOVERIES IN 2020

Research findings presented at Scoliosis Research Society Annual Meeting



PATRICK CAHILL, MD

Dr. Cahill studied Prolonged Post-Operative Intubation Following Spinal Fusion in Cerebral Palsy. He determined three Risk Factors: pre-operative Body Mass Index, history of pneumonia and intra-operative blood loss for prolonged intubation and demonstrated that prolonged intubation is associated with numerous additional peri-operative medical complications.

Dr. Cahill also evaluated the Impact of Spinal Deformity and Surgery on Health-Related Quality of Life in Cerebral Palsy. In this prospective longitudinal cohort study of scoliosis associated with cerebral palsy, he reported that health related quality of life (HRQoL) was improved at 24 months for patients who underwent a spinal fusion compared to a non-operative control group.



BURT YASZAY, MD

With Dr. Yaszay's research effort he asked the clinical question, "Does the upper instrumented vertebrae have to be T2 in CP Patients Undergoing Spinal Fusion for their Neuromuscular Scoliosis?" He found that outcomes between patients fused to the second thoracic vertebrae (T2) (the "gold standard") vs patients fused to the third or fourth Thoracic vertebrae (T3/T4) resulted in similar radiographic and clinical outcomes.



SUKEN SHAH, MD

Dr. Shah performed a matched cohort study to compare severe CP scoliosis patients treated with anterior release and PSF versus PSF alone. He found that patients treated with anterior release demonstrated decreased curve correction on flexibility radiographs, correcting less than 30%. Patients treated with anterior release had similar postoperative scoliosis and pelvic obliquity correction, but experienced longer hospital stays and increased complications. In severe CP scoliosis, despite the associated morbidity, anterior release may still be indicated in curves demonstrating less than 30% flexibility.

Dr. Shah also evaluated Proximal Junctional Kyphosis (PJK) After Spinal Deformity Correction in Cerebral Palsy and found that 12.8% of patients developed PJK and 8% underwent reoperation. Patients with PJK were more likely to be hyperkyphotic preop and without severe cognitive impairment. PJK does have a negative effect on patient reported outcomes.



Peter Newton, MD

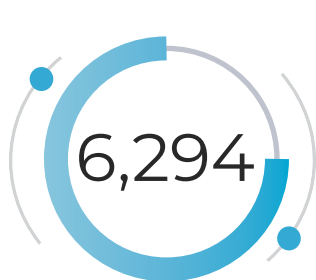
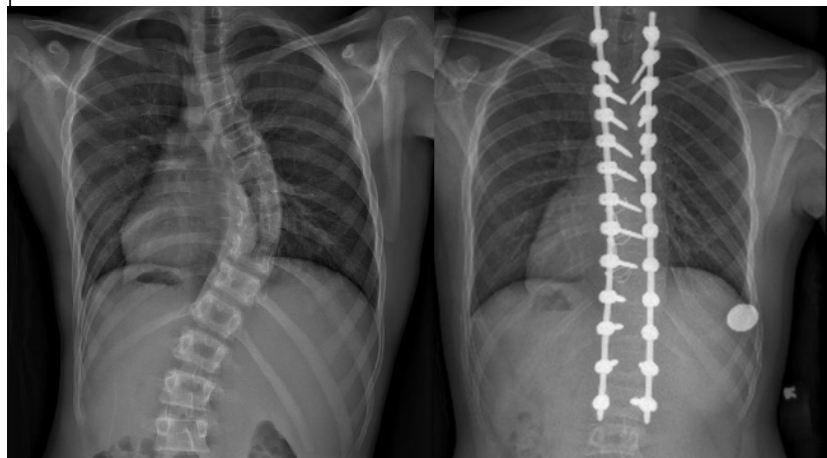
Primary Investigator

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, Inc., and EOS Imaging.**

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.



**OPERATIVE PATIENTS
DATA COLLECTED**



**NON-OPERATIVE
PATIENTS DATA
COLLECTED**



**PATIENTS HAVE 10-YEAR
POST-OPERATIVE DATA
COLLECTED**



**RESEARCH SITES
PARTICIPATE BY
CONTRIBUTING PATIENT
DATA**

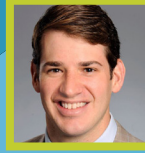
RESEARCH DISCOVERIES IN 2020

Research findings presented at Scoliosis Research Society Annual Meeting



LARRY LENKE, MD

Dr. Lenke evaluated Selective vs. Non-Selective Thoracic Fusion for Lenke Type 1-4C Curves, to determine which has More Complications at 5-Year Follow-up. Selective thoracic fusion is associated with lower short- and long-term complications compared to non-selective thoracic fusion. It did not increase the rate of reoperation rate for residual lumbar deformity.



NICK FLETCHER, MD

Dr. Fletcher analyzed patients treated with a selective fusion where the lowest instrumented vertebrae was proximal to the stable sagittal vertebrae. In these patients, he found a 15% incidence of DJK at five years of postoperative follow up compared to 2.2% of patients fused distal to the SSV. Surgeons should take the stable sagittal vertebrae into account when planning selective thoracic fusion to avoid DJK and the possibility of revision surgery.



STEVEN HWANG, MD

3D imaging has improved our understanding of rotation in AIS surgery and allows us to better measure surgical derotation achieved. Dr. Hwang, sought to determine if single or dual rod derotation is associated with greater apical derotation. He compared 452 patients with Lenke 1-4 curves, and found 73.1% of patients achieved > 50% improvement in apical rotation or thoracic rib prominence. Greater pre-op rotation and institution-specific factors were most predictive of improvement in apical rotation. Single vs dual rod derotation, metal type, implant density, osteotomies, and other radiographic variables were not associated with greater correction.

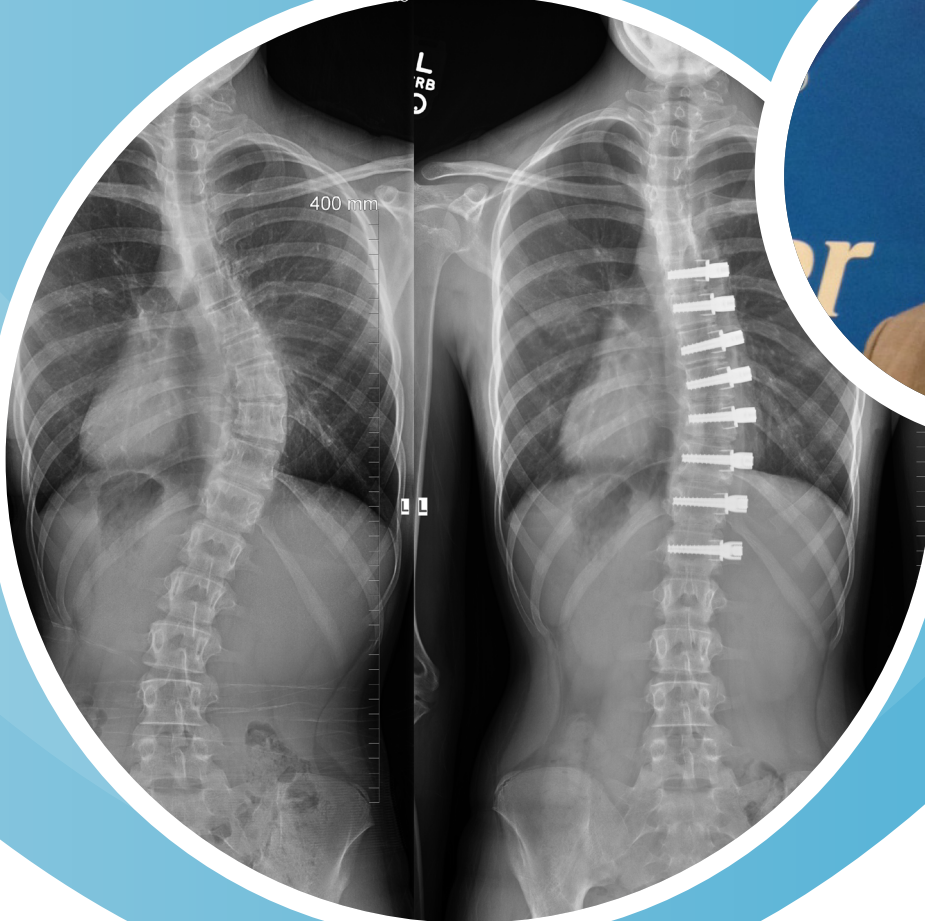


AMIT JAIN, MD

There is substantial variability in the use of bone grafts and substitutes within this large cohort of AIS patients who underwent spinal fusion in our HSG Idiopathic Scoliosis database registry. Dr. Jain evaluated the use of bone graft substitutes or extenders (BS) in spinal fusion surgery and found they did not reduce the rate of reoperation or pseudarthrosis. However, the use of bone graft substitutes or extenders was associated with higher incidence of wound related complications.

SCOLIOSIS **NON-FUSION** RESEARCH STUDIES

Peter Newton, MD

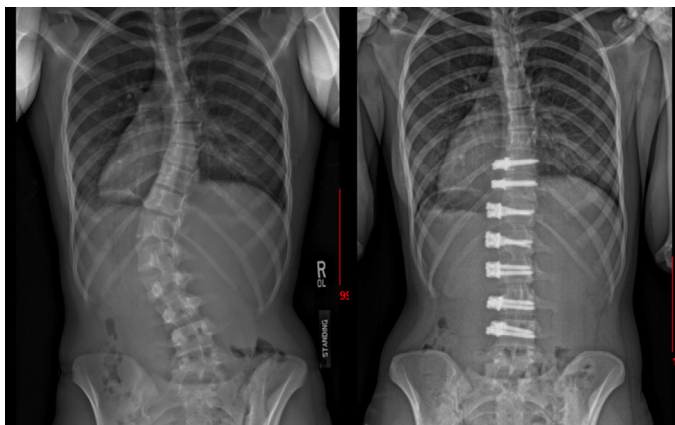


Retrospective Multi-Center Study of the Outcomes of Anterior Vertebral Body Tethering for Spinal Deformity Correction

- ✓ Principal Investigator: **Peter Newton, MD**
- ✓ 11 international sites participating.
- ✓ >300 patients' data included.
- ✓ Post-operative data collected up to 8 years following surgery.

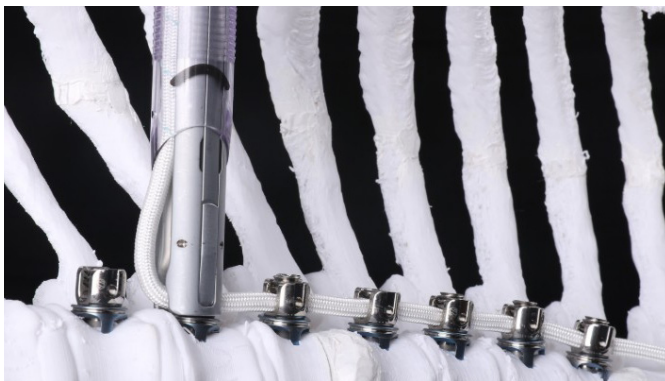
Non-Fusion Spinal Deformity Correction in Idiopathic Scoliosis- A prospective, multi-center registry study of the Harms Study Group

- ✓ Principal Investigator: **Amer Samdani, MD**
- ✓ 15 international sites participating.
- ✓ Annual planned enrollment of >150 patients
- ✓ Post-operative data collected up to 25 years post-operatively.



The Tether™ – Vertebral Body Tethering System Post Approval Study

- ✓ The Harms Study Group is assisting Zimmer Biomet in conducting their HDE POST APPROVAL STUDY
- ✓ 200 patients followed for 5 years postoperatively.
- ✓ 10 U.S. sites are participating.
- ✓ FDA required for device approval compliance.



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FDA COLLABORATION

Harms Study Group Collaboration with the Food and Drug Administration (FDA)

Survey Study to Understand Patient Preferences Surrounding Spine Surgery

Since 2012, the FDA has been soliciting proposals to advance the state of the art within various areas through a specialized contract mechanism known as FDA's Broad Agency Announcement (BAA).

In 2020, the FDA awarded a 5 year research contract (BAA) to the Harms Study Group. Research scientists at the FDA, Mayo Clinic and Duke University are collaborating to administer a patient preference survey that will be used to understand patient preferences in scoliosis treatment, specifically fusion versus non-fusion surgical treatment approaches.

- ✔ Primary Investigators: **Noelle Larson, MD & Baron Lonner, MD**
- ✔ 7 participating research sites.
- ✔ 525 surveys to be collected from Pediatric Idiopathic Scoliosis patients.
- ✔ The results of this patient preferences survey will provide the FDA, industry and clinicians with crucial data regarding how patients and families value various factors including preservation of spinal motion and growth when deciding among surgical treatment options for pediatric idiopathic scoliosis.

Development of a Shared-Decision Making Tool

As the second part of the FDA contract, the Mayo Clinic Shared Decision Making National Resource Center will assist SSS and HSG to develop and test a Shared Decision Making tool (decision aid) to be used with patients and families considering fusion surgery vs. motion sparing growth modulation surgery.

- ✔ 4 participating research sites.
- ✔ Video acquisition of 40 'usual care' consultation visits between patients and surgeons in which scoliosis treatment options of fusion surgery vs. motion sparing growth modulation surgery are discussed
- ✔ The recordings will then be observed by Mayo Clinic Knowledge Evaluation Research (KER) Unit in Rochester, MN, led by **Dr. Victor Montori** and **Dr. Juan Brito Campana**.



Noelle Larson, MD



Baron Lonner, MD

Picture of FDA members exhibiting at 2019 Power Over Scoliosis in Philadelphia .

David Gebben, PhD,
Heather Benz, PhD,
Vincent J. Devlin, MD,
Elizabeth Adegboyega-Panox, MD,
CAPT Raquel Peat, PhD, MPH, USPHS

2020 FISCAL YEAR REVENUE & SUPPORT

**INDUSTRY RESEARCH
STUDY SPONSORS
DONORS** & ALL INCOME:

INDUSTRY/SOCIETY
RESEARCH GRANTS

82%

CHARITABLE DONATIONS

12%

INVESTMENT INTEREST

3%

DATABASE

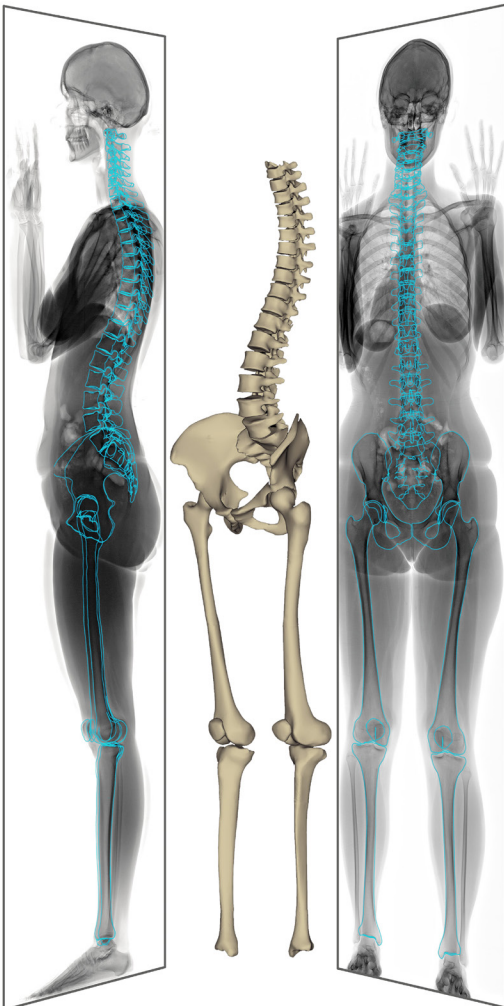
3%

SPONSORSHIPS

0%

SPECIAL EVENTS/
EDUCATION

0%



■ Sponsorships and Special Events did not occur in 2020 due to the Pandemic.

FINANCIAL REPORT

FUNCTIONAL EXPENSES



83%

RESEARCH & STUDY
EXPENSE

85%

EIGHTY-FIVE

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



TO IMPROVING
COUNTLESS
CHILDREN'S LIVES

9%

MANAGEMENT &
GENERAL

6%

FUNDRAISING EXPENSE

2%

PATIENT EDUCATION
EXPENSE

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Gutierrez, Lisa
Heiss-Tiplady, Lori
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Malone, Dan
Marks, Michelle &
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Mattle, Benjamin
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Rice, Brian
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Sucato, Daniel, MD
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We Pay - Coin Up

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Richardson, Nancy
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Each patient with a spine deformity has a unique story to tell. Setting Scoliosis Straight has shared over 86 inspirational stories from patients who have had spinal treatment and wish to give hope to others.

Sharing your story with these 3 easy steps.



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your personal experience and journey with scoliosis.



SEND

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



SHARE

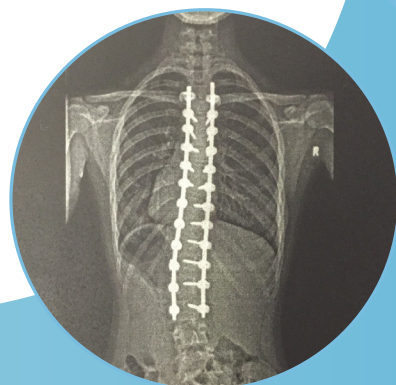
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to visit our Patient Story page or submit your own story today.





RACHEL LIAN

I was diagnosed with Adolescent Idiopathic Scoliosis in 2013, when I was 12 years old. Although my spine had been straight less than a year earlier at my annual physical appointment, I suddenly had a curvature of over 50 degrees. It seemed as though my entire world came crumbling down. As a teenager, this diagnosis made self-acceptance seem impossible. At the same time, as a dancer, tennis player, and musician, it was difficult to think about not being able to continue these beloved hobbies.



SCAN QR CODE
to read Rachel full story
and interview.



2020 HSG ACCOMPLISHMENTS



Dr. Suken Shah was presented with the Russell A. Hibbs Clinical Research Award for his research entitled, “*Complications following posterior surgical treatment of Adolescent Idiopathic Scoliosis: Prospective 10-year Follow-up Study*” at the annual Scoliosis Research Society Meeting.

CONGRATULATIONS DR. SHAH!

Dr. Burt Yaszay was bestowed with the Louis A. Goldstein Clinical Research award for his e-Poster: “*Definitve Fusions are Better than Growth Friendly Procedure for Juvenile Patients with Cerebral Palsy and Scoliosis: A Prospective Comparative Cohort Study*” at the annual Scoliosis Research Society Meeting.

WELL DONE DR. YASZAY!



Dr. Firoz Miyanji's abstract entitled, “*Vertebral Body Tethering: Truly Motion Preserving or Rather Motion Limiting?*” and **Michelle Marks's** abstract entitled, “*Does a Surgeon's Performance and patient outcomes improve with Dashboard Reporting?*” were both nominated for

IMAST PRESTIGIOUS WHITECLOUD AWARD.

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.

01

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

02

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

03

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

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

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to learn how to get started
with the programs below.



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Funds2orgs is the leading shoe drive fundraising company in North America. When you collect gently worn, used, and new shoes, you eliminate all out-of-pocket costs, and you get everything you need to hold a shoe drive fundraiser.



COIN UP

Donate your spare change with the Coin-Up App! Select Setting Scoliosis Straight, link your bank card and set a monthly limit. Watch spare change from everyday purchases make a big change for children with spinal deformities.

 **spreadshirt**

You can purchase Setting Scoliosis Straight swag through our partnership with Spreadshirt. Spreadshirt offers a variety of products and a portion of your purchase will benefit SSSF.

gofundme
CHARITY

GoFundMe Charity is a subscription free fundraising platform with powerful tools to make fundraising easy for charities. Start a fundraiser with GoFundMe Charity today!

DAFDIRECTSM
Directly connecting donors to charitable causes

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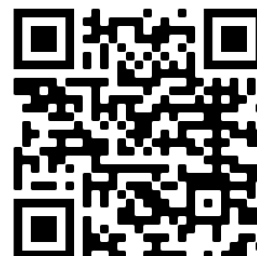
UPCOMING EVENTS IN 2021

■ FOUR WEBINARS

This year we will be holding four webinars designed to educate and inform patients, and their families. The webinars are hosted by **Harms Study Group** surgeons, who are key opinion leaders in the world of spinal surgery. They will present evidence-based information on various topics about scoliosis treatment options, and advancements in patient care. Webinars will include patient/parent panel discussions where attendees can ask questions.

SCAN QR CODE

for more news and update about these events.



SAVE
THE
DATE

FUTURE WEBINARS IN 2021:

April 8, 2021

Ask The Experts

June 5, 2021

Power Over Scoliosis

September 11, 2021

Power Over Scoliosis Intl

December 2, 2021

Vertebral Body Tether

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Infographic Handbook



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TRACEY BASTROM
Statistician



MARY DALUPANG
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HEIDI FERNANDEZ
Research Assistant



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ALAN SANCHEZ
Administration Assistant
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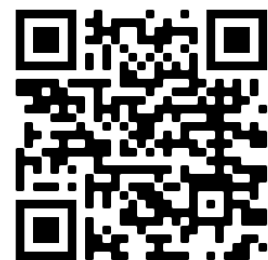
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