



Supporting Discoveries in Spinal Deformities

2017 ANNUAL REPORT



**“EDUCATING AND IMPROVING
OUR PATIENTS AND THEIR
FAMILIES OUTCOMES ARE OUR
MOTIVATION AND INCENTIVE
FOR CREATING THE MOST
ADVANCED RESEARCH IN SPINAL
DEFORMITY”**

- David Clements, MD



Peter Newton, MD

President, Setting Scoliosis Straight Foundation

Dear Friends,

I remain inspired by the efforts of the patients, families, healthcare providers and the researchers that relentlessly promote the advancement of scoliosis treatment. Research, Education and a focus on Quality are at the core of the Setting Scoliosis Straight Foundation mission. All of you have played a role, and I am grateful for the contributions you've made in advancing scoliosis treatment. We are poised to take the work of 2017 to the next level in 2018! Thank you for your support and encouragement as we work towards a world free of disability due to spinal deformity.

Most Sincerely,

A handwritten signature in blue ink, which appears to read "Peter Newton". The signature is fluid and cursive.



Michelle Marks, PT, MA

Executive Director, Setting Scoliosis Straight Foundation

Dear Friends,

I am filled with gratitude for the many blessings that our organization received in 2017. In spite of difficult economic times, we were fortunate to develop new industry partnerships and privileged to host the Give BACKS Hope event; both provided much needed funding for our research and patient education efforts. Our talented surgeon members, research staff and foundation infrastructure produced scoliosis research to improve treatment outcomes and education to enhance patient care. I am appreciative of our patients and families who participate in our research and who strive forward as scoliosis ambassadors to spread awareness, fundraise and share their stories. I am excited for 2018 as we expand our quality initiatives and bring people together around our shared values. Thank you for your support!

Most Sincerely,

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FOUNDATION FAMILY

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

For this reason, Setting Scoliosis Straight formed the **Foundation Family**— comprised of grateful families and caring friends who want to come together to raise awareness and support for a cause that has been severely underrepresented. What started as a small group of eager volunteers has transformed into a country-wide network of over 500 Foundation Family members!



We want to offer a huge and heartfelt **THANK YOU** to our Foundation Family, for your unwavering energy, enthusiasm, and support throughout the years. You have provided lift to our mission and fill us with great purpose each day. We couldn't do it without you and it's been an honor sharing this journey with you.



If you are interested in being part of our Foundation Family, visit our website and sign-up today!

www.settingscoliosisstraight.org

RACHEL LIAN

GRATEFUL PATIENT & SSS VOLUNTEER & FOUNDATION FAMILY MEMBER

DESCRIBE WHAT IT WAS LIKE TO LEARN YOU HAD SCOLIOSIS

When I was seven the doctors found a really small curvature in my spine, so we decided to monitor it. When I was 12, I was at the pool one day and my parents noticed that my trunk was shifted and shoulders were uneven, so my parents scheduled an appt with my doctors and found that I had a 50 degree curvature. Seeing my x-rays was shocking. I just couldn't believe I was looking at my spine.

WHAT KIND OF SUPPORT WAS HELPFUL TO YOU DURING THIS TIME?

It's natural to begin talking about treatment right away, focusing on what to do to fix the problem. But, what helped me is speaking to someone my age that had gone through it and had encouraging advice to provide.

WHAT IS ONE PIECE OF ADVICE YOU WOULD GIVE TO A NEWLY DIAGNOSED PATIENT?

The main piece of advice I can give is to be open about treatment options. I wore three different types of braces. I also did physical therapy and chiropractic treatments, which isn't proven to work, but it helped me stay open-minded. Doing your research about treatment options and being open-minded is important and also being open-minded about surgery, if that's the last option, is important too. I know talking about surgery is scary, but sometimes the sooner you get it fixed the less painful and the more of the spine you can save.

WHAT WAS IT LIKE COMMUNICATING WITH YOUR SURGEON?

Dr. Newton was great. He was very thorough and explained everything to me and my parents from his technique, to what instrumentation he was going to use and why. He made me feel like I was part of the decision-making process and it really made a difference. It definitely helps to keep an open dialogue with your doctor or surgeon.

RACHEL IS A GIRL SCOUT GOLD AWARD RECIPIENT, ONE OF THE MOST PRESTIGIOUS AWARDS GIVEN. WHAT WAS IT LIKE TO RECEIVE THIS AWARD?

I wanted to give back to the scoliosis community and let patients and families know that they're not alone and also as a way to help them maintain a more positive outlook on their situation amidst having scoliosis. For my project, I made a scrapbook diary which documented my life with scoliosis from doing different treatments and progresses made, as well as preparing for surgery and what it was like in the hospital and throughout recovery. I also showed a progression of my scar which I know is a big question that is asked by patients who are undergoing corrective surgery. It also shows how active I am today. I can play soccer and play the viola. The takeaway message I hope patients feel when they read my scrapbook is that it's going to be ok, and they will come out on the other side of this so much stronger.



BOARD OF DIRECTORS



Peter Newton, MD
President & Chairman



David Clements, MD
Vice President



Robert Stone, CPA
Treasurer



Michelle Marks, PT, MA
Secretary



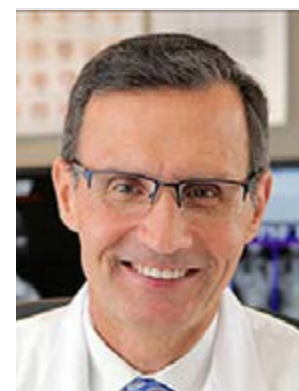
Randal Betz, MD



Thomas Errico, MD



Stacey Goldfarb, Esq.



Lawrence Lenke, MD



Baron Lonner, MD



Alan Olsen



Amer Samdani, MD



Kevin Sayar, Esq.



Suken Shah, MD



Harry Shufflebarger, MD



“Initially agreeing to serve on the BOD of Setting Scoliosis Straight seemed like a logical extension of my career devoted to surgical correction of Scoliosis and other Spinal Deformities. I have now come to realize it is a privilege.”

- Thomas Errico, MD

WHO WE ARE



Supporting Discoveries in Spinal Deformities

The Setting Scoliosis Straight Foundation (SSSF), formerly known as Harms Study Group Foundation (HSG), is a not-for-profit charitable foundation established in 2008. Its purpose is to conduct fundraising efforts in support of the Harms Study Group, with a goal to further support and advance techniques in the treatment of spinal deformities in children and adolescents worldwide.

In 2018, Setting Scoliosis Straight has grown over the first decade of existence. Strategies have been employed to meet the growing goals of our organization while raising the bar in patient education establishing best practice guidelines in patient care.

CURRENT STRATEGIC PLAN GOALS

GOAL #1

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

GOAL #2

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

GOAL #3

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



Having a family member touched by Scoliosis has helped me appreciate the need that exists." "I look forward to doing my part as a member of this great organization by supporting the efforts of the doctors and researchers who work together to improve patient outcomes as it relates to Scoliosis."

- **Howard Greenberg,**
Patient dad and scoliosis ambassador

WHAT WE DO

SETTING SCOLIOSIS STRAIGHT



SUPPORT

Change happens when BIG ideas are supported by lots of small efforts. Due to the collective choice of scoliosis ambassadors from all over the country, we are empowering and advocating on behalf of children living with spine deformity. Become an SSS ambassador today and use your talents and skill set to help others!



EDUCATION

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



RESEARCH

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

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POWER OVER SCOLIOSIS & GIVE BACKS HOPE

2017's educational and fundraising events, **Power Over Scoliosis** and **Give BACKS Hope**, were held on Saturday, June 3, in beautiful Miami, Florida.

These events brought together the best and brightest in the orthopedic industry along with scoliosis patients and their families from all over the country to learn from each other's personal experiences and lean on one another for mutual support. Traveling across the country to put on two massive events on the same day was no small undertaking, but the end result was a brilliant collaboration between Miami's finest institutions, esteemed faculty, passionate parents, volunteers, and of course our incredible scoliosis patient ambassadors.

Power Over Scoliosis co-chairs, **Drs. Stephen George and John Asghar of Nicklaus Children's Hospital**, recruited an incredible faculty team comprised of HSG members, local surgeon colleagues, nurse practitioners, and patient speakers! Topics covered included: Predicting Scoliosis Progression, Does Bracing Really Work?, and Choosing the Right Surgeon for You. In addition to expert presentations, patient ambassadors for Marfans and cerebral

palsy prepared individual presentations about their condition, allowing audience members to glean from their personal experiences and wisdom.

Directly following the course, medical professionals, grateful patient families and community leaders assembled at the Biltmore to raise awareness and fundraising support for pediatric spine research. The highlight of the evening was honoring our great friend and colleague, **Dr. Harry Shufflebarger**, for his guiding hand in pioneering spine research and lifelong dedication to his patients and medical community. Guest speakers included SSSF spokeswoman, **Lindsay Ellingson**, and patient ambassador, **Allesandra Maggioni**. The success of this event was made possible due to the incredible efforts of our Miami special events committee and event chair, **Teresa Haskett**.

Special thanks to everyone who supported these events! Your presence and contributions demonstrated the importance and need for continuous patient education and spine research.

“I simply could not get over the surgical talent and knowledge that congregated in that one place. It was a parent’s dream team, and to be able to have such access to their wisdom was amazing. I hope you continue to do these sessions in other cities.”

~ Program Attendee &
Patient Mom

Courtney Rone
Scoliosis Patient &
Guest Speaker

When parents, families,
and members of the
community come together
for an important cause,
**all children
benefit.**



“Thank you all for including my mom and I in this event. It was an incredibly special weekend for us both- it’s nice to feel like part of a community who gets it!”

~ Kelly Anderson
Scoliosis Ambassador
& Guest Speaker

FUNDRAISING OPPORTUNITIES

Every patient, every parent, and every doctor we meet deepens our understanding of the impact scoliosis has on a child and their family. And if we're lucky, they'll share their story with us too.

By listening to the stories of people who've been personally affected, we're able to place ourselves in their shoes, constantly learning new ways we can help the scoliosis community. Like an ocean current, your stories guide our vision, getting us closer to a healthier, happier future for all children with scoliosis.

CALLING ALL STORYTELLERS!

When done from the heart, and in a place of storytelling, fundraising has the power to effect significant change.

If you would like to spread awareness in your community by sharing your own triumphant story, we encourage you to start your own fundraising campaign. It's quick and easy, and most of all, rewarding. You set the parameters and fundraising goal and we'll support and promote your efforts every step of the way.

Visit our website to learn how to start your very own fundraiser today!

www.settingscoliosisstraight.org



HOW IT WORKS

THE BIG PICTURE OF RESEARCH AND ITS IMPACTS

Supporting research allows our surgeon researchers to unlock the door to new discoveries in spinal deformity patients, patient treatment and care.



WHAT WE DO

HARMS STUDY GROUP

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

Through comprehensive prospective research studies, questions regarding treatment approach, techniques, and desired outcomes are studied.

All research is done with a commitment to be internationally recognized for the highest quality published research on spinal deformity surgery techniques and patient outcomes.



YOUR ROLE IN RESEARCH

WHAT DOES IT MEAN TO SUPPORT RESEARCH

Pediatric research does more than fill in the gaps of the unknown. It requires us to **SEEK out inefficiencies and make the impossible, **POSSIBLE**. It is knowledge gained through research that **PROPELS** us into a future of even greater possibilities; where children with scoliosis are more than just healthy and happy, but truly **THRIVING** in every sense of the word.**



“One of the biggest reasons why I believe patients choose to be part of research is because they directly benefitted from the individuals and families that have come before, all those years ago, and said Yes. Said YES to participating in a clinical trial, YES to coming in for follow-up appointments, YES to having their data collected. I’ve just come to admire the people who say YES, and if I could thank them all individually, for all the time that they’ve given I would.”

– **Amy Kager**,
Nurse and scoliosis ambassador



“I just see it as being a partner with researchers and helping to improve treatments and quality of life for other patients. Everyone has been a patient, or has cared for someone with scoliosis, and the experience we’ve had from diagnosis through treatment in our lives, gives us something unique and important to say around that table with researchers as partners.”

– **Diana Moll**,
Patient mom and scoliosis ambassador

HSG CORE MEMBERS



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

Hubert Labelle, MD
CHU Sainte-Justine
Montreal, Canada



Stefan Parent, MD, Ph.D.
CHU Sainte-Justine
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Cincinnati, Ohio

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Ethianum Klinik Heidelberg,
Germany

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

SCIENTIFIC PRESENTATIONS



TRAVELING AROUND THE WORLD!

The Harms Study Group had a huge presence this year at four 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. Surgeon members of the HSG presented 4 podium presentations at the American Academy of Orthopaedic Surgeons (AAOS), 10 podium presentations at the Scoliosis Research Society (SRS), 8 podium presentations at the Pediatric Orthopaedic Society of North America (POSNA), and 10 podium presentations at the International Meeting on Advanced Spine Techniques (IMAST).



SCIENTIFIC PUBLICATIONS

1. Murphy JS et al. Predictors of distal adding-on in thoracic major curves with AR lumbar modifiers. *Spine (Phila Pa 1976)* 42(4):E211-8, Feb. 15, 2017.
2. Lonner BS et al. MRI screening in operative Scheuermann kyphosis: is it necessary? *Spine Deform* 5(2):124-33, Mar. 2017.
3. Lonner BS et al. Resource utilization in adolescent idiopathic scoliosis surgery: is there opportunity for standardization? *Spine Deform* 5(3):166-71, May 2017.
4. Fletcher ND et al. Development of consensus-based best practice guidelines for postoperative care following posterior spinal fusion for AIS. *Spine (Phila Pa 1976)* 42(9):E547-54, May 1, 2017.
5. Lonner BS et al. Risk factors of proximal junctional kyphosis in adolescent idiopathic scoliosis—the pelvis and other considerations. *Spine Deform* 5(3):181-8, May 2017.
6. Jain A et al. Recurrence of deep surgical site infection in cerebral palsy after spinal fusion is rare. *Spine Deform* 5(3):208-12, May 2017.
7. Parvaresh KC et al. Predicting 3D thoracic kyphosis using traditional 2D radiographic measurements in adolescent idiopathic scoliosis. *Spine Deform* 5(3):159-65, May 2017.
8. Yaszay B et al. The effects of the three-dimensional deformity of adolescent idiopathic scoliosis on pulmonary function. *Eur Spine J* 26(6):1658-64, Jun. 2017.
9. Bennett JT et al. Factors affecting the outcomes in appearance of AIS surgery in terms of the minimal clinically important difference. *Eur Spine J* 26:1782-8, Jun. 2017.
10. Sullivan TB et al. Thoracic idiopathic scoliosis severity is highly correlated with 3D measures of thoracic kyphosis. *J Bone Joint Surg Am* 99(11):e54, Jun. 7, 2017. doi: 10.2106/JBJS.16.01324.
11. Le Naveaux F et al. 3D rod shape changes in adolescent idiopathic scoliosis instrumentation: how much does it impact correction? *Eur Spine J* 26(6):1676-83, Jun. 2017.
12. Ahmed SI et al. 5-year reoperation risk and causes for revision after idiopathic scoliosis surgery. *Spine (Phila Pa 1976)* 42(13):999-1005, Jul. 1, 2017.
13. Bartley CE, et al. Perioperative and delayed major complications following surgical treatment of adolescent idiopathic scoliosis. *J Bone Joint Surg Am* 99(14):1206-12, Jul. 19, 2017.
14. Le Naveaux F et al. Are there 3D changes in spine and rod shape in the 2 years after adolescent idiopathic scoliosis instrumentation? *Spine (Phila Pa 1976)* 42(15):1158-64, Aug. 1, 2017.
15. Pasha S et al. Timing of changes in 3D spinal parameters after selective thoracic fusion in Lenke 1 adolescent idiopathic scoliosis: 2-year follow-up. *Spine Deform.* 5(6):409-15, Nov. 2017.
16. Newton PO et al. Patient specific-risk adjustment improves comparison of infection rates following posterior fusion for adolescent idiopathic scoliosis. *J Bone Joint Surg Am* 99(21):1846-50, Nov. 1, 2017. doi: 10.2106/JBJS.16.01442.
17. Souder C et al. Factors in surgical decision making for thoracolumbar/lumbar AIS: it's about more than just the curve magnitude. *J Pediatr Orthop* 37(8):e530-5, Dec. 2017.
18. Jain A et al. Incidence of and risk factors for loss of 1 blood volume during spinal fusion surgery in patients with cerebral palsy. *J Pediatr Orthop* 37(8):e484-87, Dec. 2017.
19. Yaszay B et al. Performing a definitive fusion in juvenile CP patients is a good surgical option. *J Pediatr Orthop* 37(8):e488-91, Dec. 2017.
20. Sullivan TB et al. Selective thoracic fusion of a left decompensated main thoracic curve: proceed with caution? *Eur Spine J* 2017 Jun 10 [Epub ahead of print].
21. Lonner BS et al. Evolution of surgery for adolescent idiopathic scoliosis over 20 years: have outcomes improved? *Spine (Phila Pa 1976)*. 2017 Jul 18 [Epub ahead of print].
22. Miyanji F et al. A detailed comparative analysis of anterior versus posterior approach to Lenke 5C curves. *Spine (Phila Pa 1976)*. 2017 Aug 1 [Epub ahead of print]
23. Jain A et al. Caregiver perceptions and health-related quality-of-life changes in cerebral palsy patients after spinal arthrodesis. *Spine (Phila Pa 1976)*. 2017 Dec. 5 [Epub ahead of print].

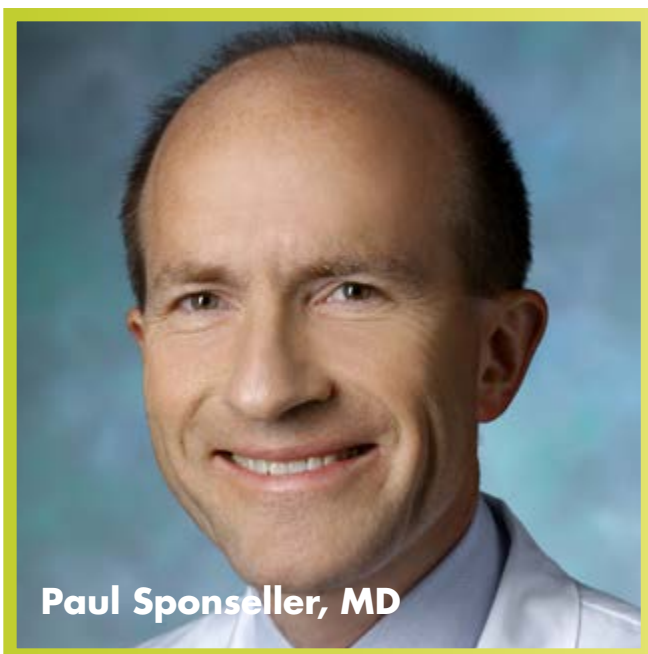
CEREBRAL PALSY SCOLIOSIS STUDY

PROSPECTIVE DATABASE REGISTRY STUDY

We are extremely grateful to the sole sponsor of this research effort, K2M, Inc.

The generous support provided by K2M enables this prospective registry to continue enrolling new operative and non-operative patients and to collect the follow-up visit data that is crucial in answering important clinical questions.

Paul Sponseller, MD, from Johns Hopkins Hospital in Baltimore, Maryland, is committed to leading this multi-center, prospective research effort.



Paul Sponseller, MD

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

*129
non-operative
patients*

*557
operative patients*

2017 RESEARCH HIGHLIGHTS: Published in the scientific literature

- Assessing the risk/benefit ratio of surgery in CP: Is surgery worth it?
- Caregiver perceptions and health-related quality-of-life changes in cerebral palsy patients after spinal arthrodesis.
- Incidence of and risk factors for loss of 1 blood volume during spinal fusion surgery in patients with cerebral palsy.
- Recurrence of Deep Surgical Site Infection in Cerebral Palsy After Spinal Fusion Is Rare.

ADOLESCENT IDIOPATHIC SCOLIOSIS STUDY

(AIS) PROSPECTIVE DATABASE REGISTRY STUDY

The purpose of this study is to analyze the long-term outcomes of surgical and non-operative treatment of adolescent idiopathic scoliosis (AIS) of all curve patterns treated by either anterior or posterior procedures. **Peter Newton, MD, from Rady Children's Hospital in San Diego**, serves as the primary investigator of this study. Co-investigators from around the country and Canada contribute patient data and collaborate to conduct annual investigations of this database registry.

The long-standing support from the primary sponsor of this study; **Depuy Synthes Spine**, has made this research effort successful. We are incredibly grateful for the ongoing research funding that Depuy Synthes Spine provides to continue prospective enrollment and collect important follow-up visit data.



Peter Newton, MD

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

553
*non-operative
patients*

5267
operative patients

2017 RESEARCH HIGHLIGHTS: Published in the scientific literature

- Development of consensus-based best practice guidelines (BPG) for postoperative care following posterior spinal fusion for AIS.
- Predictors of Distal Adding-On in Thoracic Major Curves with AR Lumbar Modifiers.
- Thoracic Idiopathic Scoliosis Severity is Highly Correlated with 3D Measures of Thoracic Kyphosis.
- Patient Specific Risk Adjustment Improves Comparison of Infection Rates Following Posterior Fusion for Adolescent Idiopathic Scoliosis.

RESEARCH PREVIEW

Every year our surgeon members query the data from our two prospective multi-center database registry studies of Adolescent Idiopathic Scoliosis and Cerebral Palsy Scoliosis. These data investigations are aimed at answering important clinical questions. We have many exciting research endeavors in the works including:

CAN 3D BE USED TO IDENTIFY RISK FACTORS FOR THE POST-OPERATIVE COMPLICATIONS OF PROXIMAL AND DISTAL JUNCTIONAL KYPHOSIS?

DOES IT MATTER WHO THE FIRST ASSISTANT IS IN SPINAL DEFORMITY SURGERY IN AIS?

WHAT IS THE SPEED OF POST-OPERATIVE CORONAL BALANCE IN AIS?

BLOOD LOSS ESTIMATES AND RISK FACTORS FOR EXCESSIVE BLOOD LOSS IN AIS SURGERY: HAVE WE BEEN FOOLING OURSELVES?

WHAT ARE THE RISK FACTORS OF EXCESSIVE BLOOD LOSS IN AIS SURGERY?

OF ALL CEREBRAL PALSY PATIENTS FUSED SHORT OF THE PELVIS, WHICH VARIABLES PREDICTED GOOD RADIOGRAPHIC RESULTS?

WHAT ARE THE OUTCOMES OF DRAIN USAGE IN AIS?

HOW HAS THE RESTORATION OF KYPHOSIS CHANGED OVER THE PAST 20 YEARS?



We are excited and proud to launch the Setting Scoliosis Straight **Surgeon Performance Program**, a quality improvement and assessment program, designed for orthopedic surgeons to assist in optimizing their performance and improving patient outcomes in Adolescent Idiopathic Scoliosis (AIS) surgery through the participation in an AIS Quality Improvement Registry and routine dashboard/feedback reporting.

THE GOALS OF THE PROGRAM ARE:

- ASSESS PATIENT & SURGEON VARIABLES ASSOCIATED WITH SURGICAL TREATMENT OF AIS
- HELP SURGEONS IDENTIFY WAYS TO IMPROVE TREATMENT PROCESSES & PATIENT OUTCOMES
- PROMOTE HEALTH CARE QUALITY IMPROVEMENT

Beta-testing of the program was initiated in October 2017 with plans to expand the program participation in 2018 to include additional US surgeons and international surgeon participants.

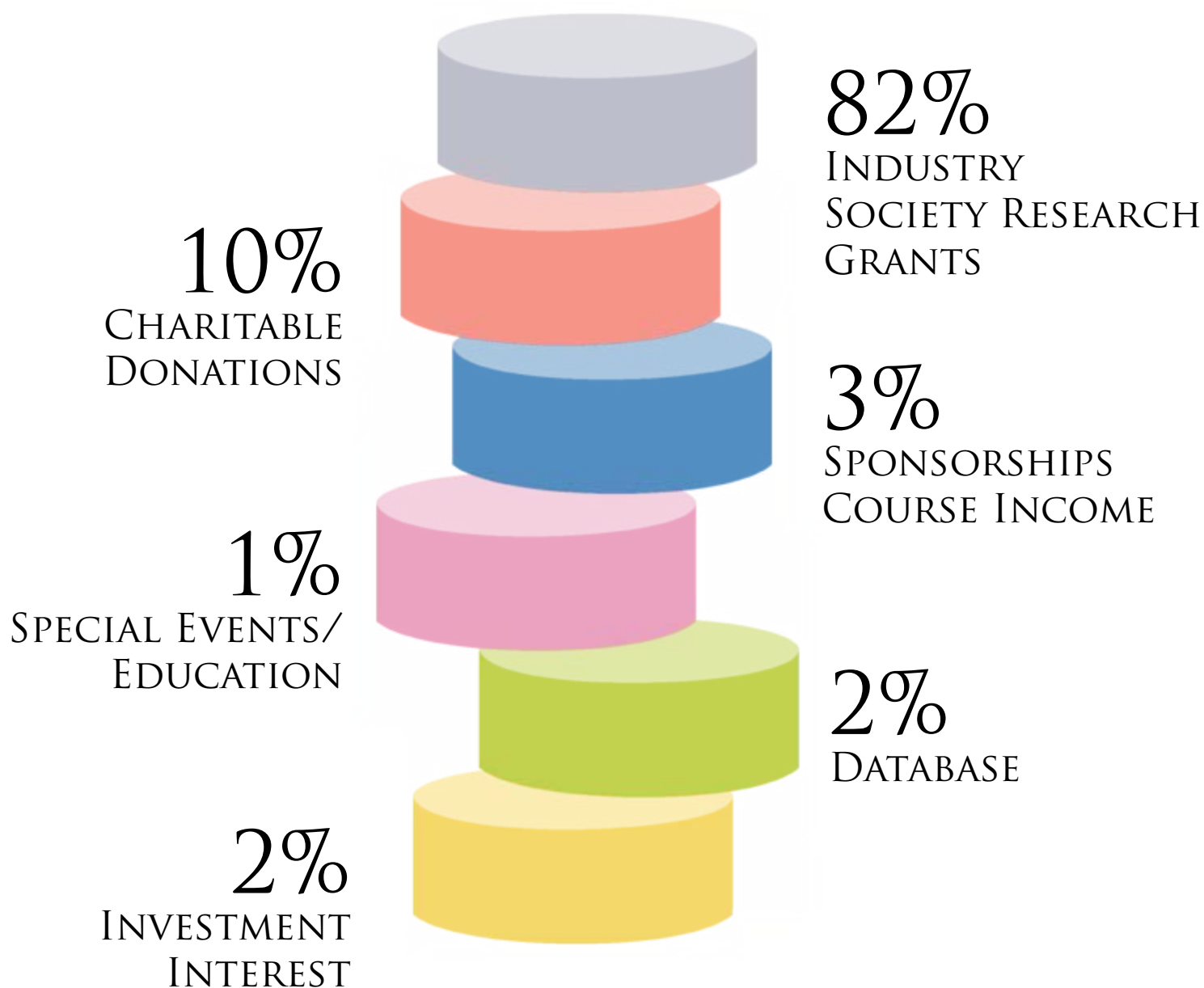
Visit our website for more information

www.hsg.settingscoliosisstraight.org

FISCAL YEAR 2017

REVENUE & SUPPORT

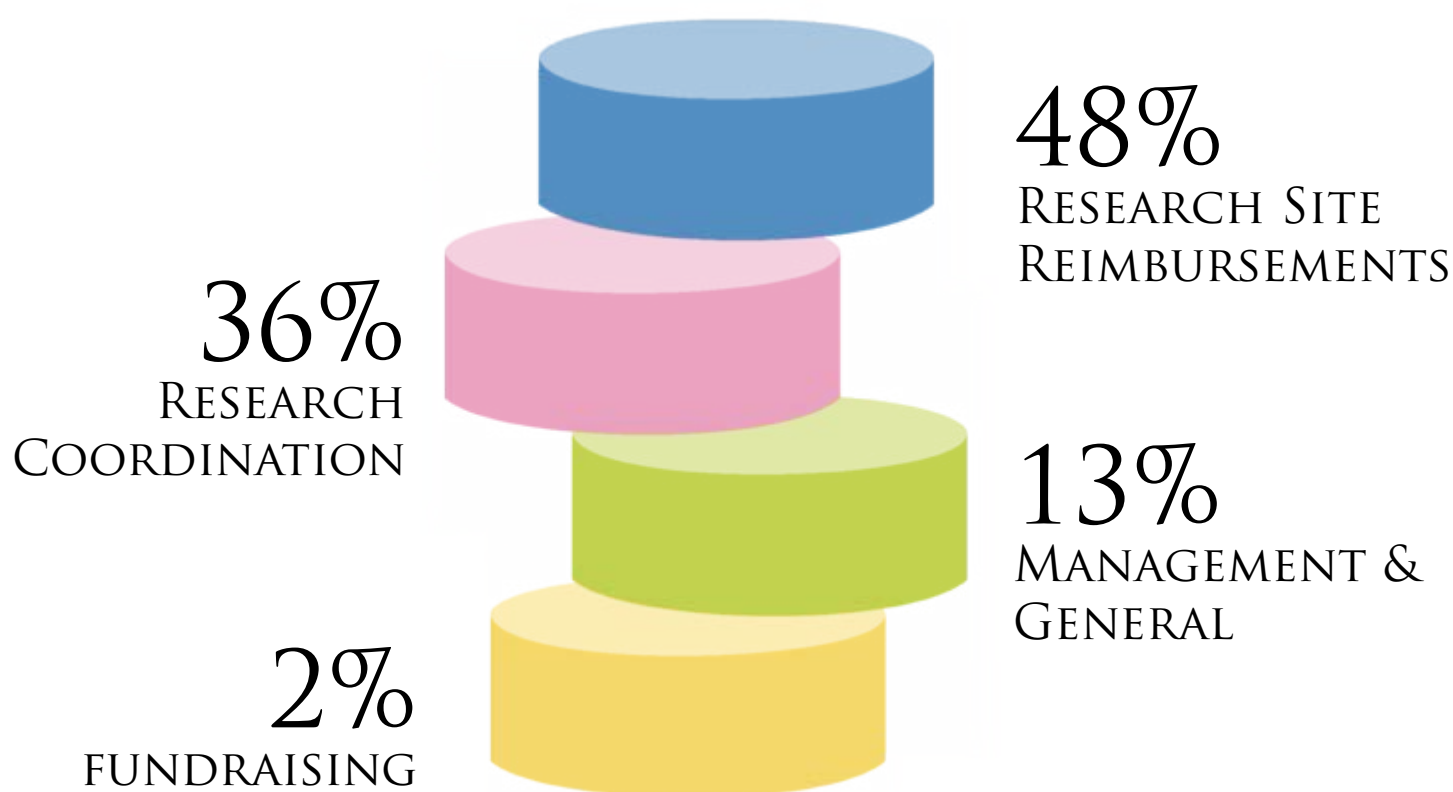
Industry Research Study Sponsors, Special Event Sponsors, Donors & all Income:



FINANCIAL REPORT

FUNCTIONAL EXPENSES

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



2017 GIVING



Diamond:
\$1,000,000+

DePuy Spine, Inc.
Johnson & Johnson Medical Products

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

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

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

Medtronic Spinal
EOS Imaging Inc.
K2M, Inc.
NuVasive, Inc

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

CHU Sainte-Justine

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

Washington University

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

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

Zimmer Biomet
Miami Children's Hospital

Supporters: \$1 - \$4,999

WITH APPRECIATION

Patron:
\$25,000 - \$49,999

Cathy & Peter Newton, MD

Fellow:
\$10,000 - \$24,999

Larry & Camille Ruvo
The Haskett Family
Bielawski & Havenick Family
DePuy Synthes
Mission Asset Management
Robert Dickinson

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

Sayar Family Foundation
The Yaszay Family
Paul Sponseller, MD
Megan & Patrick Cahill, MD
Faith Read Xenos
Cynthia & Harry Shufflebarger, MD
The Flynn Family

WITH APPRECIATION (Cont.)

Ambassador:

\$1,000 - \$4,999

Betsy & Randal Betz, MD
 Michael Kelly, MD
 Robert & Linda Jamieson
 InData Services Co.
 Nasrin & Behrooz Akbarnia, MD
 Munish Chandra Gupta, MD
 Steven Hwang, MD
 Alan Olsen
 Baron Lonner, MD
 Tamara & David Clements, MD
 Jeffrey & Stacey Goldfarb
 John Ambrose, Jr.
 Beth & Larry Lenke, MD
 Peter Sturm, MD
 Robert & Michele Stone
 The Shah Family
 Thomas Errico, MD
 Fox & Roach Charities
 PayPal Giving Fund
 Maggie and Stephen Dimino
 Alvin Crawford, MD
 The Samdani Family
 Mark Abel, MD
 David & Anita Kauffman
 Frank Carreras
 Lloyd George Foundation
 Mario Gleijeses
 Stefan Parent, MD, PhD
 Barbara & Todd Albert, MD
 World of Pink Foundation

Friend:

\$500 - \$999

Jeannine Quinn
 Josh Pahys, MD
 Deanne Elizabeth Vitiello
 Abby & Jose Portuondo
 Anonymous
 Eric Somers, MD

Hanger Clinic San Diego
 James & Marja Margolis
 Joanne Powell
 Kevin & Barbara Smole
 Michael Glotzbecker, MD
 Michael Vitale, MD, MPH
 Michelle Koehler
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 Richard and Catherine Julian
 Ronald DeMeo, MD

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 Traci Baun
 Lyndon Lee
 Petya Yorgova
 Rose Sharon Spector
 Sally Lynch-Bedell
 Tiffany Corbett
 Macys East



EMM ARUDA

SSS SPOKESWOMAN

Emm Arruda, only 16 years old when she was launched into a bustling modeling career, is redefining the ideals of beauty in one of the world's hardest businesses to crack, the fashion industry.

Emm Arruda was diagnosed with scoliosis at just 15, and opted for spinal fusion corrective surgery at SickKids Hospital in Toronto. After having two titanium rods and over 20 screws placed in her back to straighten the spine, Emm had a long but successful recovery which resulted in a two-inch height increase and close to perfect posture.

Shortly after her surgery, her mother's friend sent photos of Emm to one of Canada's leading model management agencies, Chantale Nadeau Model Placement, where she was signed right away. While some modeling agencies may have viewed her scar as a setback, Chantale describes Emm as an "incredible bionic woman with better posture than anyone she's ever known".

Since then she has flown all around the world working for some of the biggest fashion houses including Chanel, Christian Dior, Louis Vuitton, Valentino, Céline, Alexander McQueen, among many others.



INTERVIEW WITH EMM ARRUDA:

GET TO KNOW THE WOMAN BEHIND THE CURTAIN

WHY IS SUPPORTING THE SCOLIOSIS COMMUNITY AND SCOLIOSIS RESEARCH IMPORTANT TO YOU?

Scoliosis research is important to me because it's something that's a part of my story and I think that my knowledge and platform is something that can be used to help others going through the same thing. It's always comforting to have support from someone who understands.

WHAT'S ONE THING YOU'D LIKE PEOPLE TO KNOW ABOUT SCOLIOSIS?

3% of the world's population has some form of scoliosis, not only is the spine affected but so are your ribs, hips, neck and other organs, this can become very damaging and lead to further issues if not looked after. It is possible to live a normal life with scoliosis.

SO REALLY, WHAT WERE YOU LIKE IN MIDDLE SCHOOL?

I was that awkward skinny tall girl who straightened her hair, wore braces and basically had no sense of style - just trying to fit in like everyone else.

WHAT OR WHO INSPIRES YOU?

People who overcome boundaries inspire me along with people who live life to the fullest without a care in the world. Also genuinely kind and selfless people!

WHAT DO YOU ENJOY DOING IN YOUR FREE TIME?

I listen to music 24/7! I love rap and hip-hop as well as pop music, and I love to draw! Art has always been something I've been passionate about. I think that's why I love modeling so much because you get to be creative and create art through your work. I've also been very into cooking and baking recently!

WHAT HAVE YOU LEARNED ABOUT YOURSELF AND ABOUT THE WORLD THROUGH MODELING?

People will often tell you that you can't do something, and road blocks will always be thrown your way, but the way you overcome those obstacles says a lot about you as a person and will only make you rise and become stronger.

INFRASTRUCTURE



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

Michelle has been with SSS since 1998.



Tracey Bastrom
Statistical Analysis
Born in: Mineola, NY

Tracey has been with SSS since 2000.



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

Maty has been working for SSS since 1999.



Noreen Gaynor
Administrative Assistant
Born in: Jamaica, NY

Noreen has been with SSS since 2014.



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

Harvey joined the SSS Team in 2010.



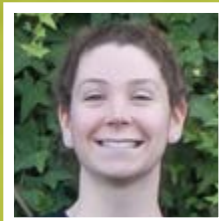
Chloe Petcharaporn
Development Manager
Born in: San Diego, CA

Chloe has been with SSS since 2015.



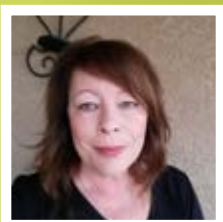
Heather Guerreso
Research Assistant
Born in: Marietta, GA

Heather joined the SSS Team in 2017.



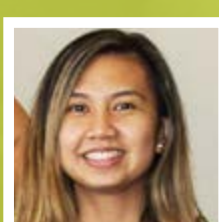
Kerry Betancourt
Research Assistant
Born in: Annapolis, MD

Kerry has been with SSS since 2016.



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

Jon Marie joined the SSS Team in 2011.



Mary Dalupang
Research Assistant
Born in: Philippines, Manila

Mary has been with SSS since 2016.

SAVE THE DATE(s) in 2018!

DESTINATION: SAN DIEGO

GIVE BACKS HOPE

Scoliosis Research & Awareness Fundraiser

Friday, June 1st | 5:30 pm to 7:30 pm

Location: International House Great Hall, UC San Diego

Register: settingscoliosisstraight.org/event/give-backs-hope

GIVE BACKS HOPE is a special event raising awareness and community support for children living with complex spine disorders. Be sure to SAVE THE DATE for this joyous occasion as we reflect on the twists and turns of scoliosis treatment advances, while helping to raise funds to support future scoliosis research discoveries!



POWER OVER SCOLIOSIS

Empowering the Scoliosis Community through Education, Advocacy & Support

Saturday, June 2nd | 9:30 am to 3:30 pm

Location: Rady Children's Hospital

Register: settingscoliosisstraight.org/event/power-over-scoliosis

Join us at Rady Children's Hospital in San Diego for our 3rd Annual POWER OVER SCOLIOSIS educational event! This family-friendly program brings together families from all over Southern California who have been impacted by scoliosis for a full day of learning, laughter, and fun!

The goal of this program is to provide families with evidence-based resources in order to make educated and confident decisions regarding treatment and care, while fostering an environment where families can openly share their stories, participate in discussions, and make meaningful connections throughout the day.



For more information, visit our website at www.settingscoliosisstraight.org or contact the SSS office at (619) 810-1430, or by email at cpetch@ssshsg.org

Setting Scoliosis Straight Foundation

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

T 619.810.1430 F 619.810.1433

Contact the Harms Study Group at research@ssshsg.org

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