



Supporting Discoveries in Spinal Deformities

2018 ANNUAL REPORT

TOGETHER WE ARE
CREATING A FUTURE
WHERE CHILDREN AND
ADOLESCENTS WITH
SPINAL DEFORMITIES
LIVE A HEALTHIER &
HAPPIER LIVES.



Dear Friends,

We are proud to offer you the 2018 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 2018, our research facilitated new discoveries that will change future patient outcomes for the better. Our network has grown to encompass 15 of the world's top scoliosis centers. More importantly, our works have been disseminated to thousands of physicians and surgeons through dozens of international scientific presentations and manuscript publications.

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 2018 and focus our attention on all that remains to be done in 2019! We appreciate your trust and dedication to our shared vision.

Most Sincerely,



Peter Newton, MD
President, Setting Scoliosis Straight



Michelle Marks, PT, MA
Executive Director,
Setting Scoliosis Straight

Dear Supporters,

We are honored to release our 2018 annual report, highlighting our efforts to improve the lives of patients with spinal deformities.

The amazing surgeon members of the Harms Study Group function in dual roles of caring for scoliosis patients today while conducting research to improve the care of future scoliosis patients. We are proud to have launched our Surgeon Performance Program – Quality Improvement Initiative to benefit surgeons across the globe and improve patient care worldwide.

The awesome patients and families who volunteer with our foundation were instrumental in raising critical funding for research and ensuring our annual patient education course succeeded in supporting newly diagnosed patients. We loved hosting this year's events in our home town, and our San Diego community is incredible!

As we look towards 2019 and beyond, we realize our work would not be possible without the support of our industry partners, our donors and our many supporters. Thank you for helping us Set Scoliosis Straight!

With Gratitude,

SETTING SCOLIOSIS STRAIGHT

Who We Are.....	1
Board of Directors.....	3
What We Do.....	4
Get Involved.....	5
Foundation Family.....	6
Ambassador Program.....	7
Patient Story: Marissa Gelbart.....	8
2018 Events.....	9
Courtney Rone & Mother.....	10
Patient Story: Chiara Faedda.....	23
SSSF Infrastructure.....	27
2019 Event Save the Date.....	28
Scoliosis Video Handbook.....	28

HARMS STUDY GROUP

Who We Are.....	11
HSG Members.....	13
Scientific Presentations.....	15
Scientific Publications.....	16
Cerebral Palsy Scoliosis Study.....	17
Adolescent Idiopathic Scoliosis Study....	18
Financial Report.....	19
2018 Giving & Appreciation.....	21
2018 HSG Accomplishments.....	25
Surgeon Performance Program.....	26



THE FOUNDATION DIVISION

of this organization:



Supporting Discoveries in Spinal Deformities

WHO WE ARE

SETTING SCOLIOSIS STRAIGHT

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.

View page 11 for more information
on our Research Division:

Harms Study Group

SHARE YOUR **STORY!**

Each patient who has spine deformity has a unique story to tell. Setting Scoliosis Straight has 28 inspirational stories from patients who have had spinal surgery and wish to share their success with others. Visit our website at www.settingscoliosisstraight.org to read them all.



Our patient stories come from all over the United States and Canada!



HSG Surgeon Barry Lonner, MD
with his patient.

"Scoliosis impacts not only the child but the entire family. The journey can be long, information confusing, bracing miserable, insurance complicated, and facing surgery terrifying. Our daughter successfully recovered from surgery and is stronger and more compassionate for it. Being part of SSS has given us comfort in belonging and helping set the next child up for success."

- **Karen & Gordon Massey**
Parents of scoliosis patient

BOARD OF DIRECTORS



Peter Newton, MD
President & Chairman



David Clements, MD
Vice President



Robert Stone, CPA
Treasurer



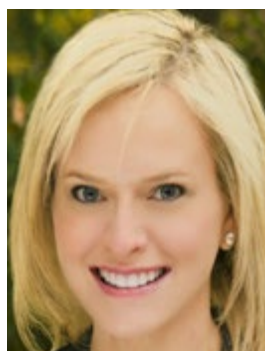
Michelle Marks, PT, MA
Secretary



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

 setting
SCOLIOSIS
straight

Supporting Discoveries in Spinal Deformities

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 spinal deformities. Become an SSS ambassador today and use your talents and skill sets to help others!



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.



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 HSG.

GET INVOLVED

HOW YOU CAN HELP...

Giving Initiatives – Monthly Contributions

Annual Giving – Annual Donations

Foundation Family – Sharing Gratitude

Fundraise – Crowdfunding

Corporate Partnership – Corporate Giving

Amazon Smile – Amazon Purchases

Vehicle Donations – Donate a Car

FUNDRAISING OPPORTUNITIES

SSSF staff works with our Ambassadors to bring about the change they want to see in their communities through fundraising initiatives, event planning, and program implementation. If you are inspired to host a fundraising event, our trained staff will be there every step of the way to help you reach your goals.

Visit our website at www.settingscoliosisstraight.org for more information.



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.

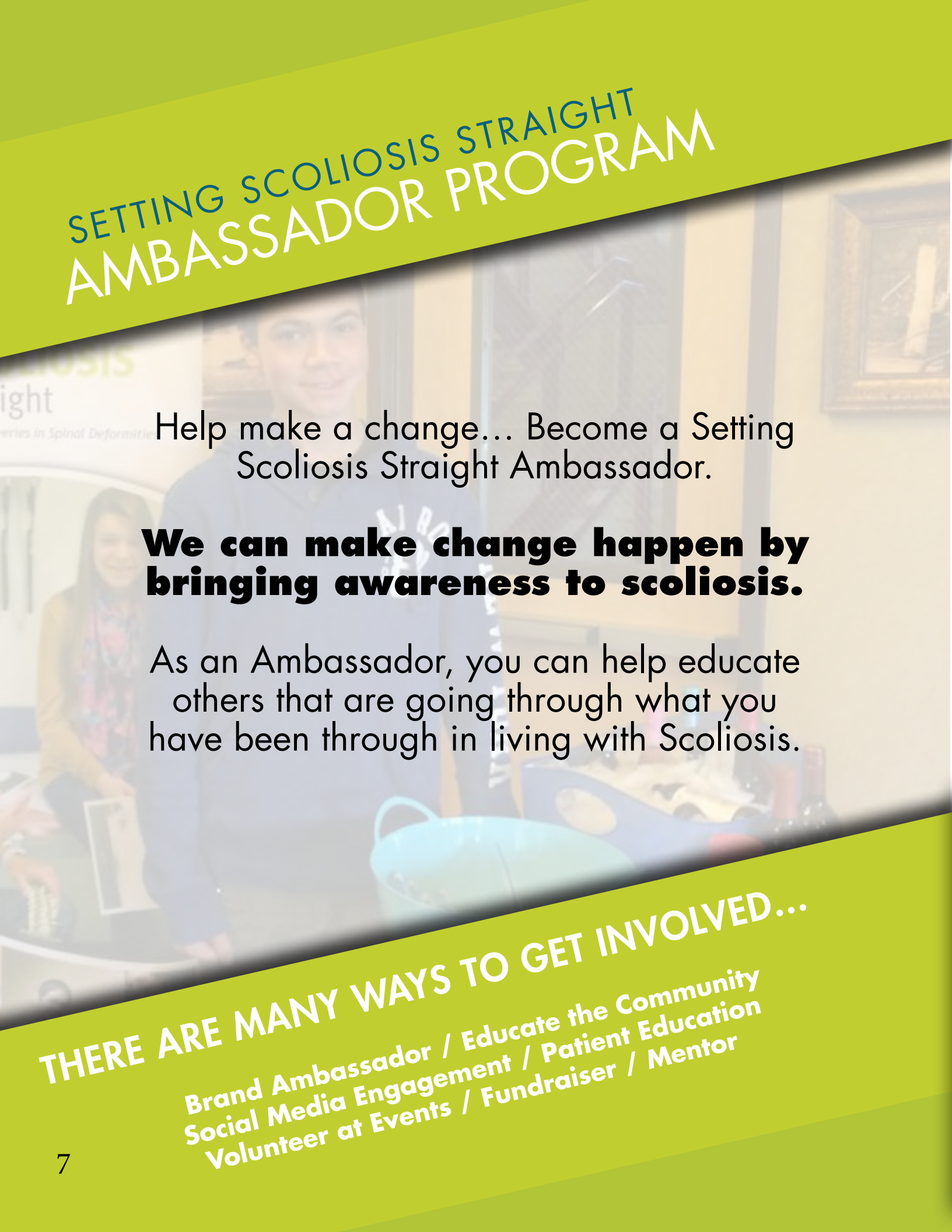
For this reason, Setting Scoliosis Straight formed the **Foundation Family**— comprised of grateful families and caring friends who want to come together to raise awareness and support a cause that has been severely underrepresented. What started as a small group of eager volunteers has transformed into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



The Gelbart Family: Eric, Marisa, Kris, and Rich Gelbart at 2018 Give BACKS Hope

Visit our website for more information!
www.settingscoliosisstraight.org





SETTING SCOLIOSIS STRAIGHT AMBASSADOR PROGRAM

Help make a change... Become a Setting Scoliosis Straight Ambassador.

We can make change happen by bringing awareness to scoliosis.

As an Ambassador, you can help educate others that are going through what you have been through in living with Scoliosis.

THERE ARE MANY WAYS TO GET INVOLVED...

- Brand Ambassador / Educate the Community
- Social Media Engagement / Patient Education
- Volunteer at Events / Fundraiser / Mentor

PATIENT STORY

MARISA GELBART

Hi everyone, my name is Marisa Gelbart and I was diagnosed with scoliosis when I was ten (fourth grade). My older brother Eric and I spent five years traveling to different surgeons, physical therapists, and specialists that would try making our scoliosis more bearable. About 3 weeks after my 15th birthday, I ended up having spinal fusion surgery done by Dr. Peter Newton and his amazing team. My last x-ray before the surgery was an all time high of 107 degrees. The surgery lasted 9.5 hours and now that it's behind me, I'm beyond grateful that I had spinal fusion.

My advice for future patients would be to remain calm and look for the positive in all of this. Even though the degree curve and surgery time seem daunting, that isn't the reality that many people face for this procedure. If anything, it's less than half of that. The point of this procedure isn't to make you think you failed with physical therapy and the brace didn't work, this is allowing you to have a more comfortable, and better quality of life.



Visit our website to read Marisa's full story.
www.settingscoliosisstraight.org

ANNUAL EVENTS

IN 2018, *SETTING SCOLIOSIS STRAIGHT* HOSTED ITS TWO LARGEST ANNUAL EVENTS: GIVE BACKS HOPE AND POWER OVER SCOLIOSIS — THIS TIME IN ITS HOMETOWN OF SAN DIEGO.

GIVE BACKS HOPE event was held at the Great Hall at UCSD overlooking the beautiful Pacific Ocean. Over \$125,000 was raised to support research for spinal deformities.

POWER OVER SCOLIOSIS, our annual education event, offered the opportunity for patients and families to learn about evidence-based treatment options for spinal deformities. Parents shared their stories to both empower and inspire newly diagnosed patients and their families.

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

Give BACKS Hope
Cochairs:



2018 Power Over Scoliosis event at Rady Children's Hospital, San Diego.

HEIDI & COURTNEY RONE

MOM & DAUGHTER DUO: FOUNDATION FAMILY

*For me, Setting Scoliosis Straight represents **POWER**. The power of knowledge, the power of support, the power of technology, the power of education, the power of networking, the power of evolution, and the power of family.*

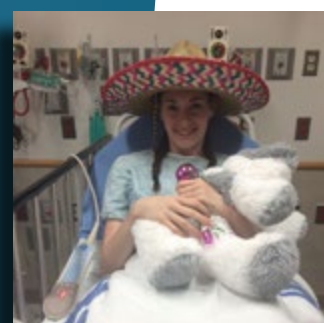
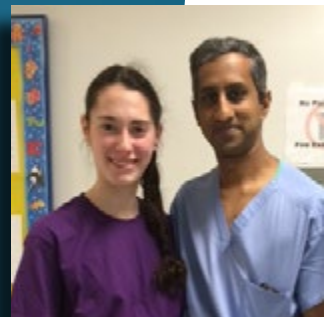
It is not about what you have, but what you do with what you have. SSSF will arm you with necessary resources to make informed, confident decisions in building a personal scoliosis treatment plan that feels right for you.

When my Courtney and I started “our” scoliosis journey, we knew the best way to prepare was through continuous education throughout the process, and have genuine faith in our support system. We needed complete assurance that the ultimate course of treatment we decided on with our doctor was best for us, and gave us the most hope for the future.

We want to remind others not to minimize their own internal power to achieve and learn. We love serving as a continued source of motivation and inspiration to the doctors, families, patients and companies that participate in the **POWER OVER SCOLIOSIS** Patient Education Course. Courtney and I have attended the annual Power Over Scoliosis Patient Education Course since its inception in 2016.

Our goals in sharing personal experiences are to provide information that instills an idea in another, lessen the fear of the unknown, familiarize a family with treatment processes, and simply being only a phone call away to comfort someone in need. We bring two unique perspectives but stand as a united front with the same objective. We know it is not only about Courtney, but also generations to follow.

We are grateful to our Setting Scoliosis Straight family for allowing us to be a part of something that is constantly getting bigger and better. We cannot wait to see what the future holds. Our family believes that we cannot necessarily change the world, but we can make a difference through the connections we make with others in our daily lives.





THE RESEARCH DIVISION

of this organization:



WHO WE ARE

HARMS STUDY 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 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 in the treatment of scoliosis.

All research is performed with the ultimate goal of improving patient outcomes.

OUR
HSG SURGEONS
FROM AROUND
THE COUNTRY
ARE DEDICATED TO
ANSWERING IMPORTANT
QUESTIONS THROUGH
RIGOROUS RESEARCH.



PATIENT & SURGEON

"The HSG has allowed me to collaborate with world renowned surgeons on a regular basis to fulfill our mission: to improve the care and lives of patients with scoliosis. As a team, our research efforts have directly translated to improvements in the care of patients all over the world. As surgeons, we have gained valuable insight from HSG's strong commitment to the longterm follow-up of our patients. I am lucky to be a member of the HSG & it has pushed me to be a better physician and researcher."

- **Josh Pahys, MD**
HSG Surgeon Member

HSG MEMBERS

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



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



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



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



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



Amer Samdani, MD
Shriners Hospitals for Children
Philadelphia, Pennsylvania



Mark Abel, MD
University of Virginia
Charlottesville, Virginia



Josh Pahys, MD
Shriners Hospitals for Children
Philadelphia, Pennsylvania



Keith Bachmann, MD
University of Virginia
Charlottesville, Virginia



Steven Hwang, MD
Shriners Hospitals for Children
Philadelphia, Pennsylvania



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



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



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



Munish Gupta, MD
Washington University
St. Louis, Missouri



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



Michael Kelly MD
Washington University
St. Louis, Missouri



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



Daniel Sucato, MD
Texas Scottish
Rite Hospital
Dallas, Texas



EMERITUS MEMBERS

Juergen Harms, MD
Ethianum Klinik Heidelberg,
Germany

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

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

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



Jean-Marc Mac-Thiong, MD
CHU Sainte-Justine
Montreal, Canada



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



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



Lawrence Lenke, MD
Columbia University
New York, New York



Ronald Lehman, MD
Columbia University
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
Scoliosis & Spine Assoc.,
Mount Sinai Hospital
New York, New York



Aaron Buckland, MD
New York University
New York, New York



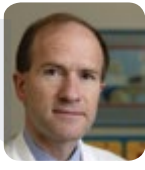
Suken Shah, MD
Nemours Alfred I. duPont
Hospital for Children
Wilmington, Delaware



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
Nicklaus Children's Hospital
Miami, Florida



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



Nicholas Fletcher, MD
Emory Orthopaedics & Spine
Atlanta, Georgia



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



SCIENTIFIC PRESENTATIONS



TRAVELING AROUND THE WORLD!

The Harms Study Group had a huge presence this year at six major annual scientific meetings and courses. These meetings 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:

- 9** presentations at the **Scoliosis Research Society (SRS)**
- 11** presentations at the **Pediatric Orthopaedic Society of North America (POSNA)**
- 5** presentations at the **International Meeting on Advanced Spine Techniques (IMAST)**
- 2** presentation at the **American Academy for Cerebral Palsy and Developmental Medicine (AACPDMD)**
- 1** presentation at the **International Society of Orthopaedic Surgery and Traumatology (SICOT)**



SCIENTIFIC PUBLICATIONS

1. Youth and Experience: The Effect of Surgeon Experience on Outcomes in Cerebral Palsy Scoliosis Surgery. Cahill et al. Spine Deformity Jan. 2018.
2. Selective thoracic fusion of a left decompensated main thoracic curve: proceed with caution? Sullivan (Yaszay) et al. Eur Spine Journal Feb. 2018.
3. Assessing the risk/benefit ratio of scoliosis surgery in cerebral palsy: is surgery worth it? Miyanji et al. Journal of Bone & Joint Surgery April 2018.
4. Relationships between the axial derotation of the lower instrumented vertebra and uninstrumented lumbar curve correction: radiographic outcome in Lenke 1 adolescent idiopathic scoliosis with a minimum two-year follow-up. Pasha (Flynn) et al. Journal of Pediatric Orthopedics April 2018.
5. Reciprocal changes in sagittal alignment with operative treatment of adolescent Scheuermann's kyphosis--prospective evaluation of 96 patients. Lonner et al. Spinal Deformity April 2018.
6. The relationship between apical vertebral rotation and truncal rotation in AIS using 3D reconstructions. Jankowitz (Newton) et al. Spinal Deformity June 2018.
7. Intraoperative traction may be a viable alternative to anterior surgery in cerebral palsy scoliosis > 100 degrees. Jackson (Cahill) et al. Journal of Pediatric Orthopedics June 2018.
8. Development of consensus based best practice guidelines for perioperative management of blood loss in patients undergoing posterior spinal fusion for adolescent idiopathic scoliosis. Fletcher et al. Spine Aug. 2018.
9. Assessment of Proximal Junctional Kyphosis and Shoulder Balance with Proximal Screws vs. Hooks in Posterior Spinal Fusion for Adolescent Idiopathic Scoliosis. Pahys et al. Spine. November 2018.
10. In search of the ever-elusive postoperative shoulder balance: is the T2 UIV the key? Brooks (Yaszay) et al. Spine Deformity. Nov. 2018.
11. Disc Degeneration in Unfused Caudal Motion Segments Ten Years Following Surgery for Adolescent Idiopathic Scoliosis. Lonner et al. Spine Deformity Nov. 2018.
12. Agreement between manual and computerized designation of neutral vertebra in idiopathic scoliosis. DeFrancesco (Cahill) et al. Spine Deformity. Nov. 2018.
13. Quality of life improvement following surgery in adolescent spinal deformity patients: a comparison between Scheuermann kyphosis and adolescent idiopathic scoliosis. (Toombs) Lonner et al. Spine Deformity Nov. 2018.
14. Three methods of pelvic fixation for scoliosis in children with cerebral palsy: differences at 5-year follow-up. Abousamra (Sponseller) Spine June 2018.
15. Ponte Osteotomies Increase the Risk of Neuromonitoring Alerts in Adolescent Idiopathic Scoliosis Correction Surgery. Buckland et al. Spine July 2018.
16. Expectations for Postoperative Improvement in Health-Related Quality of Life in Young Patients With Lumbosacral Spondylolisthesis: A Prospective Cohort Study. Bourassa-Moreau (Mac-Thiong) et al. Spine July 2018.
17. Factors associated with surgical approach and outcomes in cerebral palsy scoliosis. Jackson (Cahill) et al. Eur Spine Journal August 2018.
18. Thoracic lordosis, especially in males, increases blood loss in adolescent idiopathic scoliosis. Abousamra (Newton) et al. Journal of Pediatric Orthopedics. Sept. 2018.
19. Cost-utility analysis of operative vs. nonoperative treatment of thoracic Adolescent Idiopathic Scoliosis. Jain et al. Spine July 2018.
20. Timing of Changes in Three-Dimensional Spinal Parameters After Selective Thoracic Fusion in Lenke 1 Adolescent Idiopathic Scoliosis: Two-Year Follow-up. Pasha (Cahill) et al. Spine Deformity. Nov. 2018.

CEREBRAL PALSY SCOLIOSIS STUDY

PROSPECTIVE DATABASE REGISTRY STUDY

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



COMPLEX SPINE
INNOVATIONS™

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

133
*non-operative
patients*

610
operative patients

Paul Sponseller, MD

Primary investigator, **Paul Sponseller, MD** leads the charge of this important multicenter study, important clinical questions are answered through this robust dataset such as:

- What is the effect of Major Complications in CP Scoliosis Surgery on Quality of Life?
- What are the outcomes of patients with hyperlordosis in CP Scoliosis?



ADOLESCENT IDIOPATHIC SCOLIOSIS STUDY

(AIS) PROSPECTIVE DATABASE REGISTRY STUDY



DePuy Synthes

COMPANIES OF *Johnson & Johnson*

We are extremely grateful to the primary sponsor of this research effort, **DePuy SynthesSpine, Inc.**

The Adolescent Idiopathic Scoliosis (AIS) Database Registry is the largest prospective series of operative outcomes in existence.

Peter Newton, MD, primary investigator leads the HSG surgeon members in answering important clinical questions, such as:

- What radiographic parameters predict good patient outcomes?
- What is the rate of Proximal Junctional Kyphosis above Lenke 5 fusions, and what are the predictors?

598

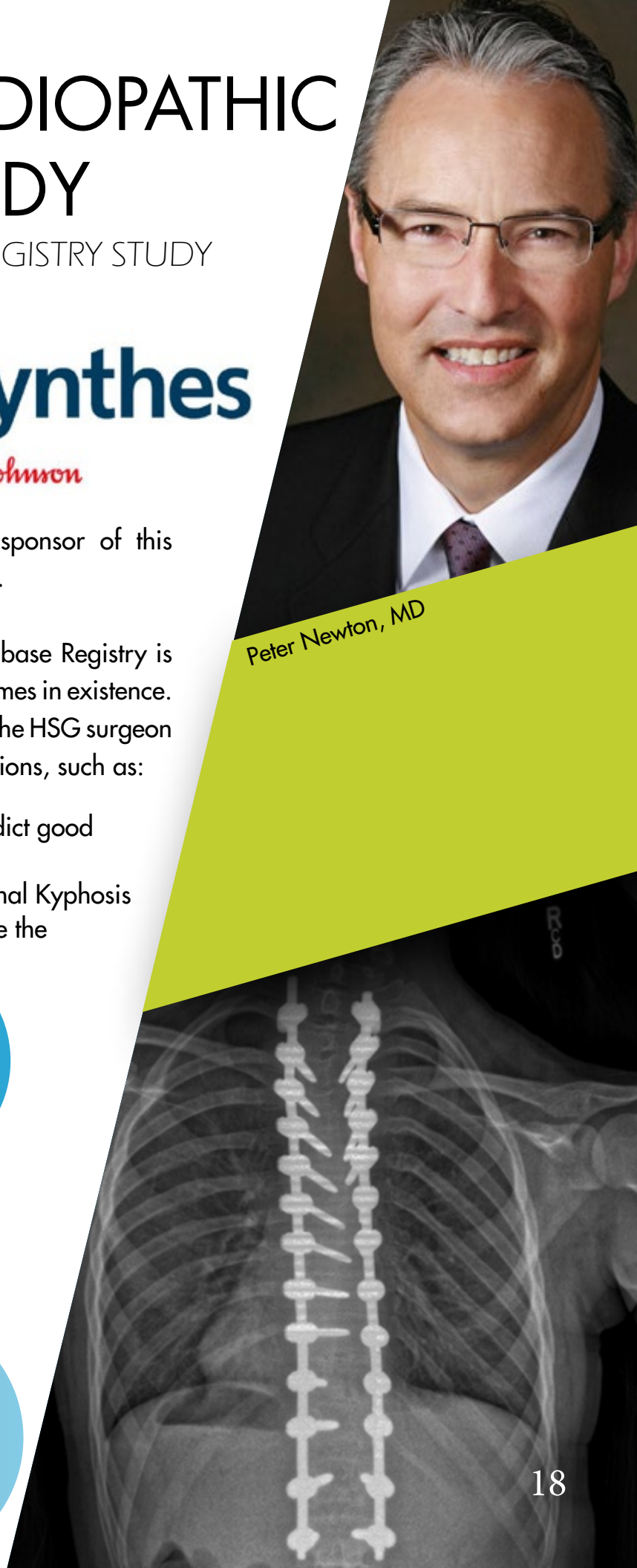
non-operative patients

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

5630

operative patients

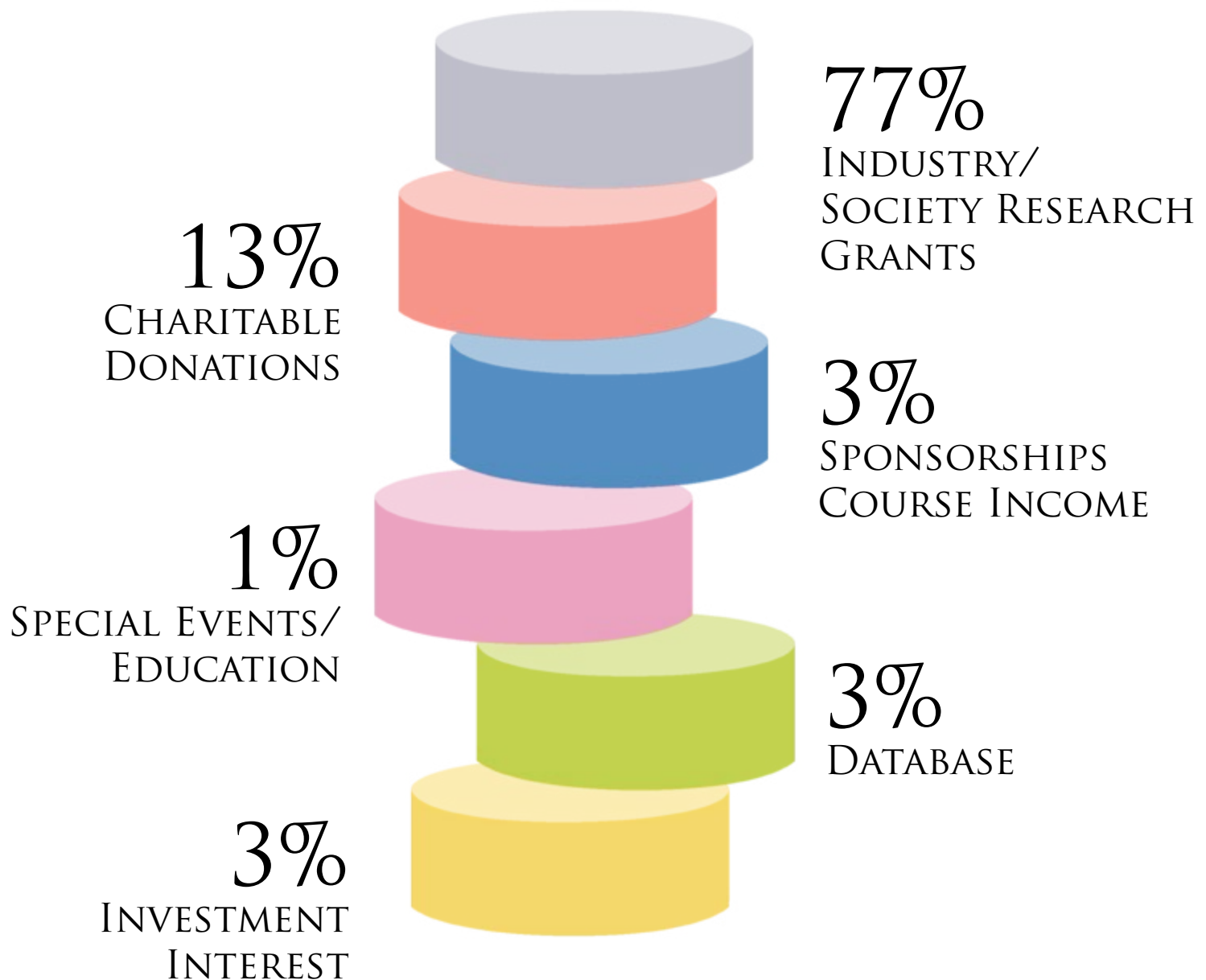
Peter Newton, MD



FISCAL YEAR 2018

REVENUES & SUPPORT

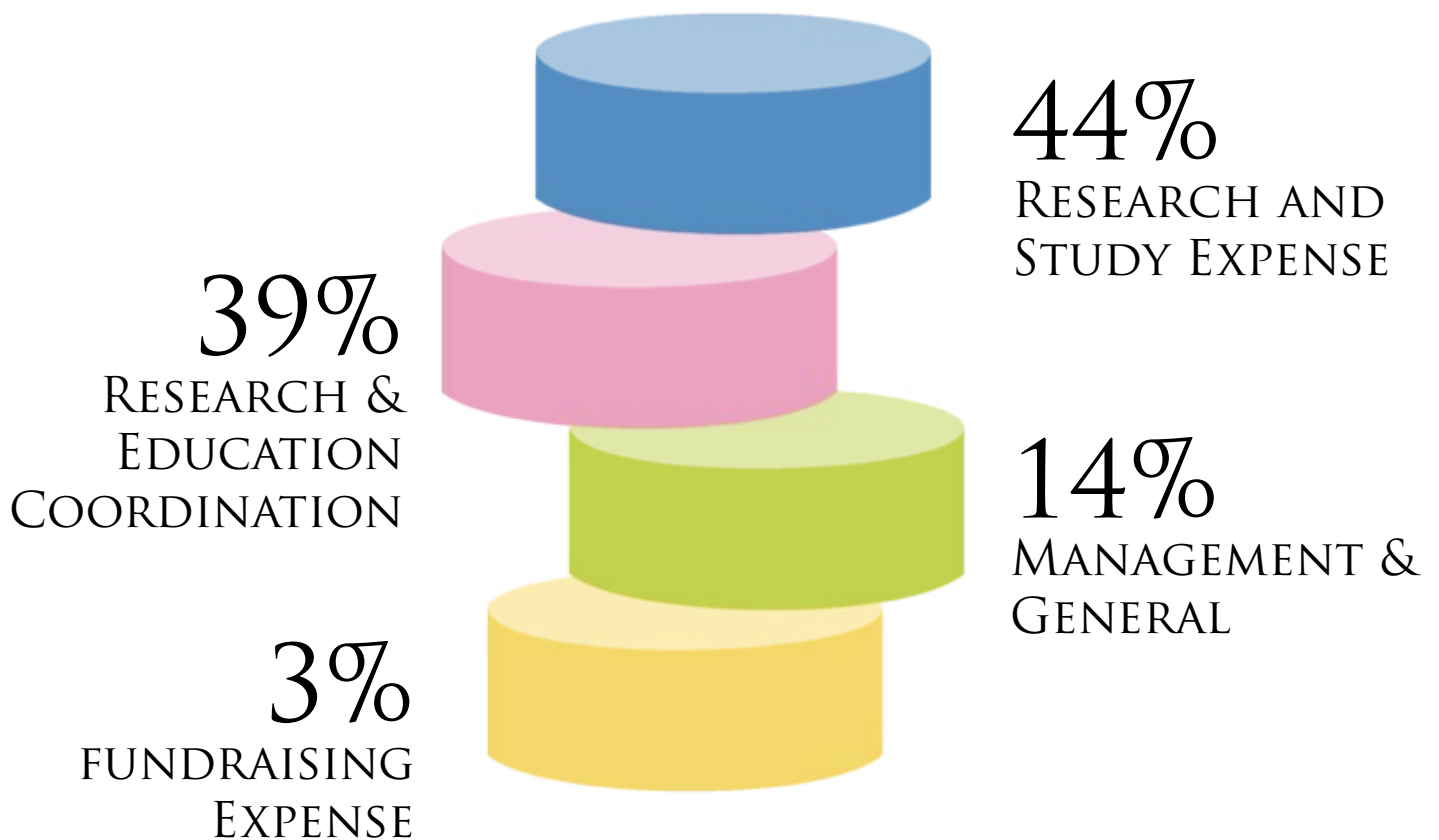
Industry Research Study Sponsors, Special Event Sponsors, Donors & all Income:



FINANCIAL REPORT

FUNCTIONAL EXPENSES

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



2017 GIVING



DePuy Synthes

Johnson & Johnson



Platinum:

\$500,000 - \$999,999

DePuy Synthes Spine, Inc.
Johnson & Johnson Medical Products

Gold:

\$250,000 - \$499,999

K2M, Inc.
NuVasive, Inc

Silver:

\$100,000 - \$249,999

CHU Sainte-Justine

Bronze:

\$50,000 - \$99,999

Copper:

\$20,000 - \$49,999

Titanium:

\$10,000 - \$19,999

Medicrea

Steel:

\$5,000 - \$9,999

Globus Medical
Scoliosis Research Society

Supporters: \$1 - \$4,999

Hanger Clinic
Medtronic Spinal
Misoniz
RPR Surgical Corporation
Sea Spine
UNYQ

WITH APPRECIATION

Patron:

\$25,000 - \$49,999

Cathy & Peter Newton, MD
Jeffrey & Stacey Goldfarb, MD
Larry & Camille Ruvo, MD

Fellow:

\$10,000 - \$24,999

Arthur M. James Family Foundation
Baron Lonner, MD
Howard & Andrea Greenberg
Michael Haskett
Paul Sponseller, MD

Advocate:

\$5,000 - \$9,999

Burt Yaszay, MD

David Clements, MD

Gelbert Family

Jennifer Bielawski & Barbara Havenick-

Magic City Casino

Johnson & Johnson PAC Match

Megan & Patrick Cahill, MD

Richard Meyer

Sayar Family Foundation

The Parker Foundation

Ambassador:

\$1,000 - \$4,999

Afshin Aminian, MD

Alvin H. Crawford, MD

Amy Kager

Arlene Bieker

Azmi Hamzaoglu

Barbara & Todd Albert

Behrooz & Nasrin Akbarnia

Benjamin Stern

Beth Eubanks

Bo & Linda Jamieson

Carrie Bower

Cindy & Geoff Weinstein

Dan Holzer

Erica W. Jamieson

Gordon Massey

Gregory M. Mundis Jr.

Harry Shufflebarger, MD

Heffernan Insurance Brokerage

Jack Flynn, MD

Keith Bachmann

Lani Owen

Lawrence Lenke, MD

Mac Multi-Family Inv.

Mark Abel, MD

Marks Family

Matt Miller

Michael Glotzbecker, MD

Michael Kelly, MD

Mike Trimm

WITH APPRECIATION (Cont.)

Network for Good
Nicholas Fletcher, MD
Nicholas Oliva
Peter Hamilton
Peter Marzano
Peter Sturm, MD
Randal Betz, MD
Rosie Greenberg
Samantha Gold
Stefan Parent, MD
Stephen Allen Jamieson
Stephen George, MD
Steven Hwang, MD
Suken Shah, MD
Vidyadhar Upasani, MD

Friend: **\$500 - \$999**

Andrew Williams
Anonymous
Benjamin Mattle
Bergman Family Fund
Brian Rice
Colleen Friedman
Danielle Huber
David Kaufer
David Wells
Deborah Hoffer
Donna & Robert Lloyd George
Eric & Karen Dasso
Jay & Cynthia Tyler
Jerry Campbell
Jesus Mendoza
Jon Stone
Joseph Rogers
Josh & Nancy Solomon
Josh Pahys, MD
Laurie L. Duffy
Matt Anderson
Matthaus Dengler
Michael & Deena Swidler
Michael Ochstein
Michael Vitale, MD
Michelle Burr
Richard & Catherine Julian
Robert & Jessica Fink
Ross Sylvia

Supporter: **\$1 - \$499**

Richard A. Kwiatkowski
Abbott Laboratories - Employees
Abigail Nakamitsu
Agatha Martindale
Alan Olsen
Alex Lam
Americas Charities
Lockheed Martin
Ana Otazua
Andrea Zon Frilli
Andrew Driver
Annalise N. Larson
Anne Barreras
Barbara Keller
Beth Berry
Beth O'Brien
Beverlee Bertinetti
Bryan Eisenberg
Caron Clay
Cathy Blalock
Chi-Kuang Feng
Chloe Petcharaporn
Christina J. Sese
Claire Stednitz
Claudia Galindo
Colleen Cavanaugh
Colleen Milne
Daniel Malave
Daniel Sinder
Danielle Fine
David L. Sponseller, MD
Dayton Smerjian
Deanne Vitiello
Debby Niethammer
Denise McLean
Douglas Wheeler
Dufour Family
Eileen Licata
Elizabeth Gimber
Ella Glassman
Eric & Susan Chortek Weisman
Esta Solomon
Fariba Rouholfadah
Frances & Mary Julian
Gerardo Guzman
Gregory & Susan Woods
Gregory Winton

Heidi Baumgartner
Henry Chambers, MD
Holly B. Bernene
Isabelle M. Marzano,
Jackie Bell
Jacqueline Bierra
James Basili
James Bennett, MD
James Garrett
Jamie Anderson
Jamie Fine
Jason S. Neumann
Jennifer & Milton Padilla
Jennifer Pitera
Jennifer Widmer
Jeremy Blain
Jessica Stokes
Jessica Thomas
John Oda
Jon Marie Basel
Just Give
Kara Robinson
Karen Franta Love
Kathleen M. Sullivan
Kathryn Abare
Kathryn E. Nichol
Keith Sequeira
Kim Sigelman
Kris Gelbert
Kristen Venuti
Kristina Case
Lamar Landry
Laurel Coil
Lauren Brown
Lauren Krichman
Lawrence Sher
Lisa Ellis
Lisa Gutierrez
Lisa Wilentz
Lorelei Sandoval
Lyla Reinero
Maria J Gaddis
Marian Miller
Marie Novo
Mark Mossuto
Martin I. Goodman
Marty Morrison
Matthew Halsey
Maureen G. Wolin
Michael & Marsha Birnbaum

Michael Marquardt
Mike Axelson
Monika Colmignoli
Mr. & Mrs. Melvin Neiss
Nelson Oliveira
Ng Bobby Kin Wah
Nicole Goret
Nishmet Carmedy
Noreen Gaynor
Patricia Burke
Paula Forbis
PayPal Giving Fund
Pooria Hosseini
Rachel Lian
Ray Weckmann
Robert Martindale
Robert Nelson
Roger Rieger
Rosa Amelia Morales
Ryan Redmond
Scott S. Russo
Shawna Gruwell
Sheila Connor
Stacey Frank
Stephanie Gunter
Sumeet Garg, MD
Tali Ginsberg
Tami Krebs
Terence Leong
Teri Furey
Timothy Cole
UnitedHealth Group
Uwe Zens
William R. Simon
Wudbhav Sankar, MD
The DuFour Family
Traci Baun
Lyndon Lee
Petya Yorgova
Rose Sharon Spector
Sally Lynch-Bedell
Tiffany Corbett
Macys East

A portrait of Maria Chiara Faedda, a woman with long dark hair, wearing a red jacket and a colorful patterned scarf. She is looking slightly to the side with a serious expression. The background is a blurred outdoor path.

MARIA CHIARA FAEDDA

PATIENT STORY

My name is Maria Chiara Faedda, from Italy. I am now 37 years old. I was diagnosed with scoliosis when I was 11, and that was when I received my first brace. I was supposed to wear it most of the day, the only exceptions were lunch, dinner and while sleeping. My scoliosis was moderate and this is the reason why the doctor decided for a brace and for constant physical therapy.

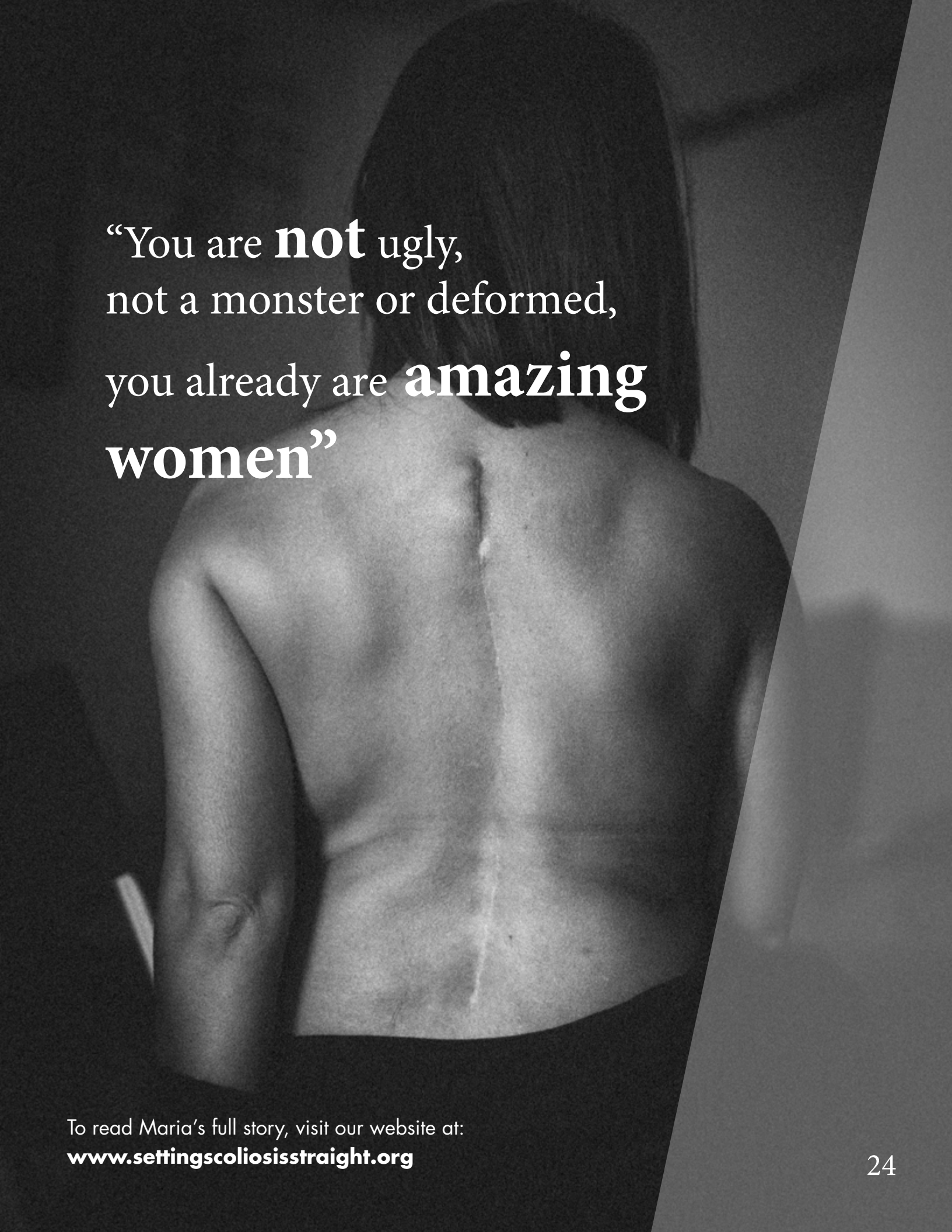
It was January 14th, and I was sitting in front of Dr. Roussoly, in his office at The Centre Médico-Chirurgical de readaptacion des Massues in Lyon, France. I clearly saw my spine x-rays hanging in front of me as the doctor said "SURGERY," and explained the procedure to my parents I started silently crying, unable to stop the tears from my eyes. Hospitals had always scared me and all of a sudden I was to be in one for a while.

June of 1999 is when I had a 5 hour surgery. The surgeons corrected the curve by inserting titanium rods on both sides of my spine to

keep it straight. After a few hours in intensive care, I was back in my room, and three days later I started walking again.

I spent two weeks in the hospital and it took six months (and a lot of physical therapy) to recover. The pain was intense and I could barely do any normal activity but it was all worth it. You never completely heal from scoliosis, you learn to live with it.

To all the girls dealing with scoliosis, do not hate your body. You are not ugly, not a monster or deformed, you already are amazing women. To my mum and dad, and to all the parents of scoliosis fighters, thank you for the constant love and support that make you the extraordinary human beings that you are. To my fiancé, the photographer who took the pictures of my scar and made it a work of art. Thank you love, for showing me the beauty of my imperfection, and teaching me to love my scar the way the you do.



“You are **not** ugly,
not a monster or deformed,
you already are **amazing**
women”

To read Maria's full story, visit our website at:
www.settingscoliosisstraight.org

2018 HSG ACCOMPLISHMENTS



Todd Albert, MD (Right) handing over the SRS Annual Presidency to HSG member **Peter Newton, MD** (left) at the Annual Scoliosis Research Society (SRS) meeting in Bologna, Italy.

HSG member **Burt Yaszay, MD** presented his abstract *"10 year Natural History of the Uninstrumented Compensatory Curve in Selectively Fused AIS"* at the SRS annual meeting. Dr. Yaszay's research won the Hibbs award for the best clinical paper.



HSG member **Paul Sponseller, MD** was voted onto the presidential line for the Scoliosis Research Society (SRS).



The **Setting Scoliosis Straight Surgeon Performance Program** is a quality improvement and assessment program designed for orthopedic surgeons to assist in optimizing their performance and improving patient outcomes.

Through participation in the AIS Quality Improvement Registry and routine dashboard/feedback reporting, surgeons can evaluate their performances and advance patient care.

The Surgeon Performance Program AIS QI Registry 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.



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



Visit our website for more information

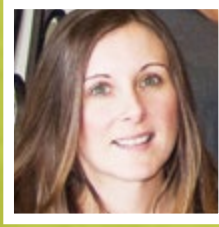
www.hsg.settingscoliosisstraight.org

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 with SSS since 1999.



Noreen Gaynor
Administrative Assistant
Born in: Jamaica, NY

Noreen has been with SSS since 2014.



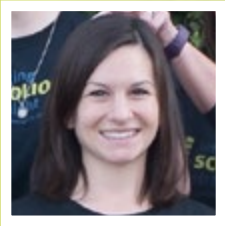
Harvey Ly
Development/Web Master/
Research Assistant
Born in: San Diego, CA

Harvey has been with SSS since 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 has been with SSS since 2017.



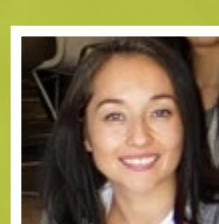
Mary
Research Assistant
Born in: Philippines, Manila

Mary has been with SSS since 2016.



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

Jon Marie has been with SSS since 2011.



Melodie Dick
Research Assistant
Born in: San Diego, CA

Melodie has been with SSS since 2017.



Jamie Anderson
Development Manager
Born in: San Diego, CA

Jamie has joined the SSS in 2018.

SAVE THE DATE(s) in 2019!

POWER OVER SCOLIOSIS

Empowering the Scoliosis Community through Education, Advocacy & Support

Date: June 1, 2019

Location: Johns Hopkins Hospital, Baltimore, MD

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

Join us in Baltimore for our 4th Annual POWER OVER SCOLIOSIS educational event! This family-friendly program brings together families from all over the country who have been impacted by scoliosis for a 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.

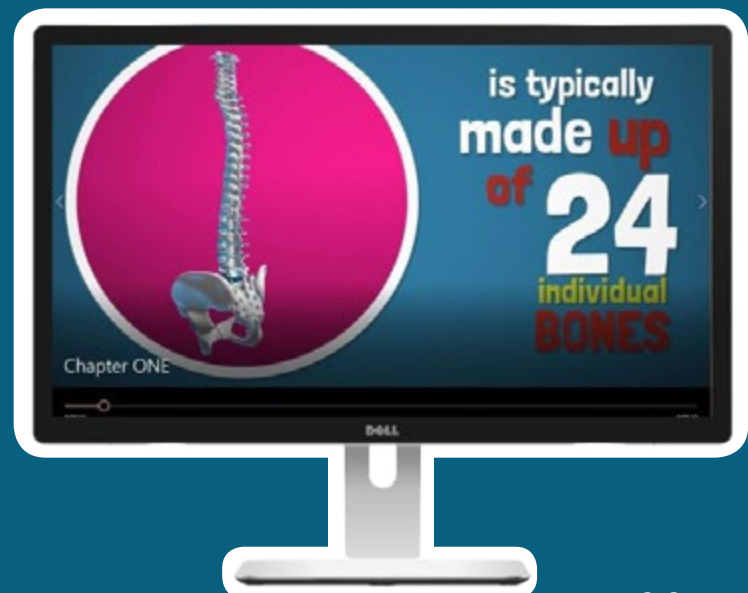


For more information, visit our website at www.settingscoliosisstraight.org or contact the SSS office at (619) 810-1430, or by email at info@ssshsg.org

SCOLIOSIS VIDEO HANDBOOK

The Setting Scoliosis Straight Foundation is proud to share our multi-chapter scoliosis video handbook to you and your family.

The core purpose for creating this video is to educate and support scoliosis patients, their families, their friends and the entire scoliosis community. Twenty-two years of research from the Harms Study Group, have been used to create this scoliosis video focused on evidence based information.



To view these videos, visit our website at www.settingscoliosisstraight.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

Follow us on:

