

# Annual Report

## 2019



PEDIATRIC  
SPINE  
STUDY GROUP

# Presidents' Message

For nearly two decades, we worked as two separate entities to improve the lives of young children with spine deformity. In 2019, the Children's Spine Study Group and the Growing Spine Study Group consolidated our efforts and became the Pediatric Spine Study Group (PSSG). With a registry of over 8,000 patients, PSSG is the leading organization in the field of immature spine deformity. This is by far the largest database of its kind in existence and includes operative and non-operative care, as well as natural history.

The strength of PSSG is in combining the experience of 147 dedicated clinicians in 46 medical centers from 12 countries. Aligned in vision and mission, we aim to create a bright future for our patients and families. The creation of the joint Study Group increases the impact of our research, the power of our advocacy, and the value of our educational outreach. Best said by child poet, Mattie Stepanek, who lived with a rare mitochondrial disorder, "Unity is strength when there is teamwork and collaboration and wonderful things can be achieved." We hope you are inspired by this report which summarizes the activities and output of our past 12 months, distribution of our members and staff, and plans for the future.

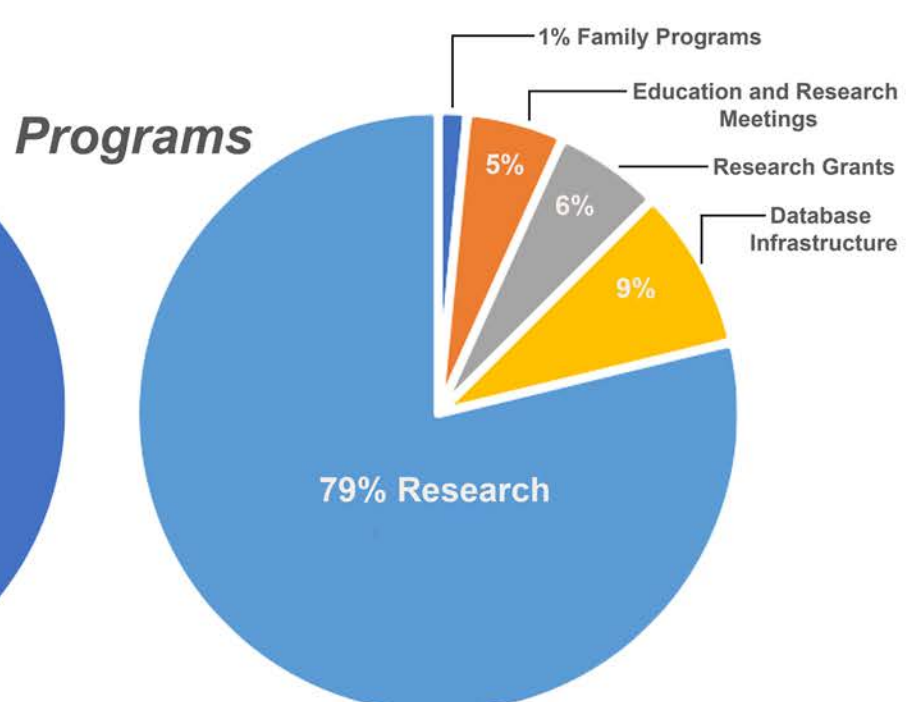
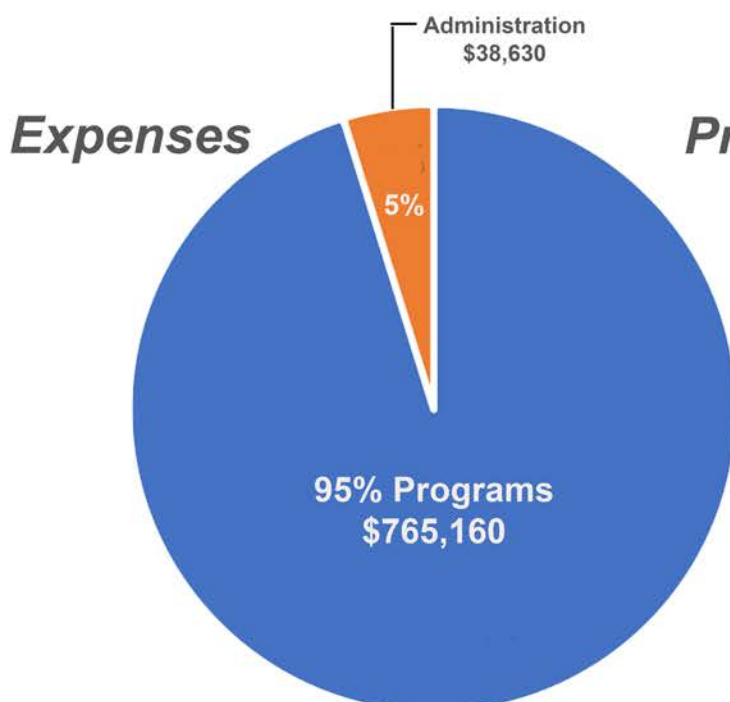
*Paul D Sponseller*

Paul Sponseller, MD

*Michael Vitale*

Michael Vitale, MD, MPH

## Financials





In 2019, the PSSG formed Research Interest Groups to focus in specific areas. Teams of approximately 10-15 researchers were assembled to formulate meaningful research questions. United by this mission, many impactful questions were answered. Some studies looked specifically at new surgical treatments for scoliosis in unique patient populations. Others asked whether surgical treatments differed in older patient populations. All research aimed at ultimately improving care for our many patients with complex scoliosis. In addition to research, the Pediatric Spine Study Group implemented many new improvements to strengthen productivity and member participation and collaboration.

alone  
we can do so little

### Dr. Ying Li: A Comparison of Posterior Spinal Fusion to Growth Friendly Surgery in Patients with Neuromuscular Scoliosis

Posterior spinal fusion (PSF) may be more effective than growth-friendly (GF) surgery at controlling neuromuscular scoliosis in 8-11 year old children. PSF patients had less complications, and showed higher Financial Impact and Family Burden scores. However, GF patients gained a greater percentage of spine length even though they started out at a younger age with a larger spinal curvature.

TOGETHER

we can do so much

- Helen Keller

### Dr. Ron El-Hawary: The Use of Magnetically Controlled Growing Rods in Children with Cerebral Palsy

While early onset scoliosis (EOS) is common in children with Cerebral Palsy (CP), the effectiveness and risk of unplanned reoperation (UPROR) for magnetically controlled growing rods (MCGR) has not yet been determined. This study showed that within the first 2 years after initial surgery, there was not a significant difference in the risk of UPROR when comparing MCGR to traditional growth-friendly surgical treatment. MCGR however was more effective at correcting scoliosis.





## Dr. Josh Murphy: Shoulder Balance in Idiopathic Scoliosis Patients Following Anterior Vertebral Body Tethering of Spine

Shoulder balance is an important factor for patient satisfaction after surgery for Idiopathic Scoliosis. 38 patients with idiopathic scoliosis (IS) that underwent anterior vertebral body tethering (AVBT) were reviewed. Looking at radiographic and clinical measurements, 13.2% of patients had shoulder imbalance  $>2$  cm. at follow up. These findings compare favorably with reports in patients who underwent selective thoracic fusion (STF).

## Research

In 2019, the PSSG kicked off the first-ever randomized control trial utilizing Magnetic Controlled Growing Rod technology. With 22 participating sites, patients will be randomized into different lengthening intervals to determine what is best for spinal growth.



## Family Support

Through our Families-In-Need program, many families across the United States can apply and be granted assistance for access to medical care. This program removes the challenges of getting to the doctor for families, so the focus can be treatment and leading better lives.



## Education

The International Congress of Early Onset Scoliosis, in November 2019, was attended by 119 clinicians from around the world. Hosted by PSSG, the conference aims to share knowledge, experience, and research among peers with the overriding goal to improve care for children with early onset scoliosis.





# Academic Productivity 2019

## Publications 2019

- Baky FJ, Larson AN, St Hilaire T, Pawelek J, Skaggs DL, Emans JB, Pahys JM, CSSG, GSSG. (2019). The Effect of Expansion Thoracostomy on Spine Growth in Patients with Spinal Deformity and Fused Ribs Treated with Rib-Based Growing Constructs. *Spine Deformity*: 7(5):836-841.
- El Bromboly Y, Hurry J, Padhye K, Johnston C, McClung A, Samdani A, Glotzbecker M, Attia A, St. Hilaire T, El-Hawary R, CSSG, GSSG. (2019). Distraction-Based Surgeries Increase Spine Length for Patients with Non-Idiopathic Early Onset Scoliosis - 5 Year Follow up. *Spine Deformity*: 7(5); 822-828.
- Grzywna A, Mclung A, Sanders J, Sturm P, Karlin L, Glotzbecker M, CSSG, GSSG. (2018). Survey to Describe Variability in Early Onset Scoliosis Cast Practices. *JCO*: 12(4):406-412.
- Helenius IJ, Saarinen AJ, White KK, McClung A, Yazici M, Garg S, Thompson GH, Johnston CE, Pahys JM, Vitale MG, Akbarnia BA, Sponseller PD. (2019). Results of Growth-Friendly Management of Early-Onset Scoliosis in Children with and without Skeletal Dysplasias: a Matched Comparison. *The Bone and Joint Journal*: 101-B(12):1563-1569.
- Joukhadar N, Kubat O, Heflin JA, Yasin MS, McClung A, Flynn T, Sheppard M, Skaggs D, El-Hawary R. (2019). Superior Extension of Upper Instrumented Vertebrae in Distraction-based Surgery: A Surrogate for Clinically Significant Proximal Junctional Kyphosis. *Spine Deformity*: 7(2): 371-375.
- Oore J, Connell B, Yaszay B, Samdani A, St. Hilaire T, Flynn T, El-Hawary R, CSSG, GSSG. (2019). Growth Friendly Surgery and Serial Cast Correction in the Treatment of Early-onset Scoliosis for Patients with Prader-Willi Syndrome. *JPO*: epub.
- Schur M, Andras LM, Murgai R, Siddiqui AA, Gonsalves NR, Sponseller PD, Emans JB, Vitale MG, Skaggs DL, GSSG, CSSG. (2019). Pelvic Obliquity Correction in Distraction-Based Growth Friendly Implants. *Spine Deformity*: 7(6): 985-991.

## Presentations 2019

- Akbarnia BA, Pawelek J, Hosseini P, Salari P, Kabirian N, Marks D, Shah S, Skaggs DL, Emans JB, Hazem E, Thompson GH, Sponseller PD. (November 2019). Traditional Growing Rod Graduates of Different Etiologic Categories have Similar Clinical and Radiographic Outcomes. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Baky F, Noelle Larson AN, St. Hilaire T, Pawelek J, Skaggs DL, Emans JB, Pahys JM, CSSG, GSSG. (March 2019). The Effect of Expansion Thoracostomy on Spine Growth in Patients with Spinal Deformity and Fused Ribs Treated with Rib-Based Growing Constructs. Poster presented at the American Academy of Orthopaedic Surgeons (AAOS) Annual Meeting, Las Vegas, Nevada.
- Bellaire L, Fedorak G, Heflin J, Klatt J, Smith JT, Sponseller P, Hedequist T, PSSG. (November 2019). Growth-Friendly Instrumentation for the Treatment of Early Onset Scoliosis in Marfan Syndrome. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Bonsignore-Opp L, Murphy J, Skaggs D, Parent S, Samdani A, St. Hilaire T, Vitale MG. (November 2019). Pediatric Device Regulation: The Case of Anterior Vertebral Body Tethering. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.

## Presentations 2019 Continued

- Buckler N, Sun M, Al Nouri M, Vaughan M, St. Hilaire T, Matsumoto H, Sponseller PD, Smith JT, Thompson G, Howard J, El-Hawary R, PSSG. (November 2019). Analysis of Health-Related Quality of Life in Cerebral Palsy Patients Treated with Growth-Friendly Surgery for Early-Onset Scoliosis. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Swarup I, MacAlpine E, Mayer OH, Flynn JM, Anari J, CSSG, Cahill PJ. (October 2019). Impact of Growth Friendly Interventions on Spine and Pulmonary Outcomes of Patients with Spinal Muscular Atrophy. Poster presented at The American Academy of Pediatrics National Conference and Exhibition, New Orleans, Louisiana.
- Helenius IJ, Saarinen AJ, White KK, McClung A, Yazici M, Garg S, Thompson GH, Johnston CE, Pahys JM, Vitale MG, Akbarnia BA, Sponseller PD. (November 2019). Similar Deformity Correction, but Limited Spinal Growth and Lower Health Related Quality of Life in Children with Skeletal Dysplasia Undergoing Growth-Friendly Management for Early-Onset Scoliosis. A Matched Comparison with Idiopathic Early-Onset Scoliosis. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Klyce W, Mitchell SL, Pawelek J, Skaggs DL, Sanders JO, Shah SA, McCarthy RE, Luhmann SJ, Sturm PF, Flynn JM, Smith JT, Vitale MG. (September 2019). Current Use in Growth-friendly Implants for Early Onset Scoliosis: A Ten-year Update. Poster presented at the 54th Annual Meeting of the Scoliosis Research Society (SRS), Montreal, Canada.
- Lark RK, Catanzano A, Vitale MG, Johnston C, Sponseller P, PSSG. (November 2019). Effects of Serial Casting with or without Bracing on Sagittal Parameters in Early Onset Scoliosis. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Larson AN, Pahys J, Woon R, St. Hilaire T, El-Hawary R, Fitzgerald R, Cheung J. (November 2019). High Inter-rater Reliability for Arm Span and Ulnar Length Measurements. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- LaValva SM, Kawakami N, Gandhi JS, Morishita K, Sturm PF, Garg S, Glotzbecker MP, Anari JB, Flynn JM, CSSG, GSSG, Cahill PJ. (September 2019). Awake serial body casting for the management of Infantile Idiopathic Scoliosis. Poster presented at the 54th Annual Meeting of the Scoliosis Research Society (SRS), Montreal, Canada.
- Li Y, Swallow J, Gagnier J, Cahill P, Sponseller P, Garg S, Thompson G, Ramo B, PSSG. (November 2019). Comparison of Single Posterior Spinal Fusion (PSF) vs Growth-Friendly (GF) Surgery in Older Neuromuscular EOS Patients. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Li Y, Graham CK, Robbins C, Thompson G, Sturm P, Emans J, Sponseller P, Glotzbecker M, CSSG, GSSG. (June & September 2019). Comparison of Serial Casting vs. Brace Treatment for Early Onset Scoliosis. Poster presented at the Michigan Orthopaedic Society Annual Scientific Program, Traverse City, Michigan, & 54th Annual Meeting of the Scoliosis Research Society (SRS), Montreal, Canada.
- Luhmann S, Skaggs D, Johnston C, Pahys J, Smith JT, Samdani A, El Hawary R, PSSG. (November 2019). Single Rod Constructs in Severe EOS Produce Similar Cobb Correction and Spinal Growth as Dual MCGR Constructs. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Marrache M, White KK, Larson AN, St. Hilaire T, Woon R, Vaughan M, Sponseller PD, PSSG. (November 2019). Does the Law of Diminishing Returns Exist in Early Onset Scoliosis with Connective Tissue Disorders? Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.





# Academic Productivity 2019

## Presentations 2019 Continued

- Matsumoto H, Ball J, Roye BD, Garg S, Erickson M, Samdani A, Skaggs D, Roye DP, Vitale MG, PSSG. (November 2019). Uncorrected Pelvic Obliquity is Associated with Lower Health Related Quality of Life in Ambulatory but not in Non-Ambulatory Patients after Surgical Treatment in Patients with Early Onset Scoliosis. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Matsumoto H, Simhon M, Garg S, Samdani A, Smith JT, Sponseller P, Vitale MG, Roye BD, CSSG, GSSG. (September 2019). Bigger is better: Larger thoracic height is Associated with Increased Health Related Quality of Life at Skeletal Maturity. Poster presented at the 54th Annual Meeting of the Scoliosis Research Society (SRS), Montreal, Canada.
- McClung A, Mundis G, Pawelek J, Kabirian N, Garg S, Yaszay B, Boachie-Adjei O, Sanders JO, Sponseller PD, Perez-Gruoso FS, Lavelle WF, Emans JB, Johnston CE, Akbarnia BA, CSSG, GSSG. (March 2019). Vertebral Column Resection for Early Onset Scoliosis: Indications, Utilization, and Outcomes. Poster presented at the American Academy of Orthopaedic Surgeons (AAOS) Annual Meeting, Las Vegas, Nevada.
- Meza BC, Smith JT, Vitale MG, Anari JB, CSSG. (September 2019). Proximal Anchor Fixation in Magnetically-Controlled Growing Rods (MCGR): What is the Impact of Anchor Selection & Density? Poster presented at the 54th Annual Meeting of the Scoliosis Research Society (SRS), Montreal, Canada.
- Mitchell SL, Pawelek J, Skaggs DL, Sanders JO, Shah SA, McCarthy RE, Luhmann SJ, Sturm PF, Akbarnia BA, Sponseller PD, GSSG. (March 2019). Characterizing Current Use in Growth-Friendly Implants for Spinal Deformity: A 10-Year Update. Poster presented at the American Academy of Orthopaedic Surgeons (AAOS) Annual Meeting, Las Vegas, Nevada.
- Murphy RF, Barfield WR, Corrigan C, Anari J, Sawyer JR, PSSG. (November 2019). Evolving Trends in the Inpatient Care of Early Onset Scoliosis. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Ramirez N. (June 2019). Law of Diminishing Return in Neuromuscular Early Onset Scoliosis Treated with a Rib to Pelvis Rib-Based Distraction Device. Poster presented at the 16th International Philip Zorab Symposium, Dublin, Ireland.
- Ramo B, McClung A, Jo C, Sponseller P, Miyajima F, Oetgen M. (November 2019). The Effect of Medical Comorbidities on subdomain scores of the Early Onset Scoliosis Questionnaire (EOSQ) Before Treatment. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Ramo B, McClung A, Jo C, Yaszay B, Andras L, Sponseller P, Oetgen M. (November 2019). Validation of the Early Onset Scoliosis Questionnaire (EOSQ) as applied to the Classification of Early Onset Scoliosis (C-EOS) Etiology Designation Before Scoliosis Treatment. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Roye B, Marciano G, Campbell M, Matsumoto H, White K, Sawyer J, Smith JT, Luhmann S, Sturm P, Sponseller P, Vitale MG, CSSG. (May 2019). Relationship Between Body Mass, Rod Diameter and Rod Fracture in Magnetically Controlled Growing Rods. Poster presented at the Pediatric Orthopaedic Society of North America (POSNA) Annual Meeting, Charlotte, North Carolina.
- Roye B, Marciano G, Matsumoto H, Campbell M, White KK, Sawyer J, Smith JT, Luhmann S, Sturm P, Sponseller P, Vitale MG, PSSG. (November 2019). Rod Diameter Does Not Influence Rod Fracture Rate after Surgical Treatment using Magnetically Controlled Growing Rods. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.

## Presentations 2019 Continued

- Roye BD, Campbell M, Matsumoto H, Pahys JM, Welborn M, Sawyer JR, Fletcher ND, McIntosh AL, Sturm PF, Gomez JA, Lenke LG, Vitale MG, CSSG. (October 2019). Consensus-Based Best Practice Guidelines (BPG) for Use of Preoperative Halo Gravity Traction (HGT) for Pediatric Spinal Deformity. Poster presented at The American Academy of Pediatrics National Conference and Exhibition, New Orleans, Louisiana.
- Roye DP, Campbell M, Matsumoto H, Brown C, Callejo F, Roye BD, Larson AN, Vitale MG, CSSG. (March 2019). To What Degree Does Surgeon Experience Matter? Predicting Risk of Surgical Site Infection in Early Onset Scoliosis. Poster presented at the American Academy of Orthopaedic Surgeons (AAOS) Annual Meeting, Las Vegas, Nevada.
- Siddiqui A, Nazareth A, Lindsay Andras L, Illingworth K, Gupta P, Vitale MG, Smith JT, GSSG, CSSG, Skaggs D. (May 2019). 18% of EOS patients Treated with MCGR have Minimal Lengthening Episodes Resulting in <1mm of Distraction. Poster presented at the Pediatric Orthopaedic Society of North America (POSNA) Annual Meeting, Charlotte, North Carolina.
- Simhon M, Roye B, Matsumoto H, Garg S, Samdani A, Smith JT, Sponseller P, Vitale MG, PSSG. (October & November 2019). Bigger is Better: Larger Thoracic Height is Associated with Increased Health Related Quality of Life at Skeletal Maturity. Poster presented at The American Academy of Pediatrics National Conference and Exhibition, New Orleans, Louisiana. And the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Skaggs DL, Akbarnia BA, Pawelek J, Matsumoto H, St. Hilaire T, Sturm PF, Perez-Gruoso FJS, Luhmann SJ, Sponseller PD, Smith JT, White KK, Vitale MG, CSSG, GSSG. (September 2019). Magnetically-controlled Growing Rod Patients Have Similar HRQOL Scores Compared to Traditional Growing Rod Patients After Two Years of Treatment. Poster presented at the 54th Annual Meeting of the Scoliosis Research Society (SRS), Montreal, Canada.
- Sun M, Buckler N, Al Nouri M, Vaughan M, St. Hilaire T, Sponseller PD, Smith JT, Thompson G, Howard J, El-Hawary R, PSSG. (November 2019). Treatment with MCGR Results in Improved Scoliosis Correction but No Difference in UPROR as Compared to Traditional Growth Friendly Surgery for Children with Cerebral Palsy. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Thompson G, Sponseller P, Emans J, Johnson C, Tran D, PSSG. (November 2019). Analysis of EOS Cases that are Resistant to Correction and Length Gain. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Varley E, Yaszay B, Pawelek J, Mundis GM, Oetgen M, Chase C, Sturm PF, Akbarnia BA, GSSG. (March 2019). The Role of Traditional Growing Rods in the Era of Magnetically-Controlled Growing Rods for the Treatment of Early-Onset Scoliosis. Poster presented at the American Academy of Orthopaedic Surgeons (AAOS) Annual Meeting, Las Vegas, Nevada.
- Verhofste B, Emans J, Miller P, Thompson G, Samdani A, Gruoso FS, McClung A, PSSG, Glotzbecker M. (November 2019). Is Growth-Friendly Surgery Effective for the Treatment of Spinal Deformity in Patients with Arthrogryposis Multiplex Congenita? Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Verhofste B, Glotzbecker M, Marks, McClung A, PSSG, Emans J. (November 2019). Spinal Deformity in Sotos Syndrome: First Results of Growth-Friendly Surgery. Poster presented at the 13th International Congress on Early Onset Scoliosis (ICEOS), Atlanta, Georgia.
- Williams BA, McClung A, Blakemore LC, Shah SA, Pawelek J, Sponseller PD, Parent S, Emans JB, Sturm PF, Yaszay B, Akbarnia BA, GSSG. (September 2019). Spinal MRI Utilization in Patients with Early Onset Scoliosis Review of a Large Multi-Center Database. Poster presented at the 54th Annual Meeting of the Scoliosis Research Society (SRS), Montreal, Canada.







# Thank You!

Together we keep important initiatives going to improve the lives of children living with spinal deformity. Thank you for your continued support!

## Leadership and Executive Committee

Behrooz Akbarnia

Laurel Blakemore

Ron El-Hawary

Jack Flynn

Mike Glotzbecker

Stefan Parent

Amer Samdani

Jeff Sawyer

David Skaggs

John Smith

Paul Sponseller

Michael Vitale

### Special Recognition:

**Mr. Hansjörg Wyss**

DePuy Synthes,  
Johnson & Johnson Co.  
Nuvasive



## Contact Us

**Website:** [www.childrensspinefoundation.org](http://www.childrensspinefoundation.org)

**Address:** PO Box 397

Valley Forge, PA 19481

**Email:** [info@childrensspinefoundation.org](mailto:info@childrensspinefoundation.org)