

Annual Report 2017





PRESIDENT'S MESSAGE

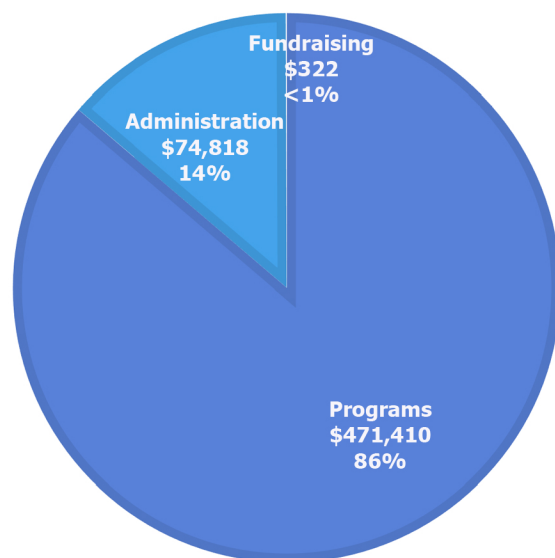
Because of your tremendous support, 2017 was a year of great progress for the Children's Spine Foundation. Beginning in January, we hosted a two-day Research Factory where leading clinicians and researchers discussed the difficult problems facing our patients with complex Early Onset Scoliosis. Working together, research questions were defined and methodology was developed. In this report our "pipeline of progress" details how 44 questions became 27 research projects that resulted in immeasurable improved outcomes for the children we treat.

Our pipeline is full. With your generosity, commitment and support, we will continue to make extraordinary progress for our 5000 patients with complex scoliosis. We are proud to share these accomplishments as we pave a better path for those yet to come.

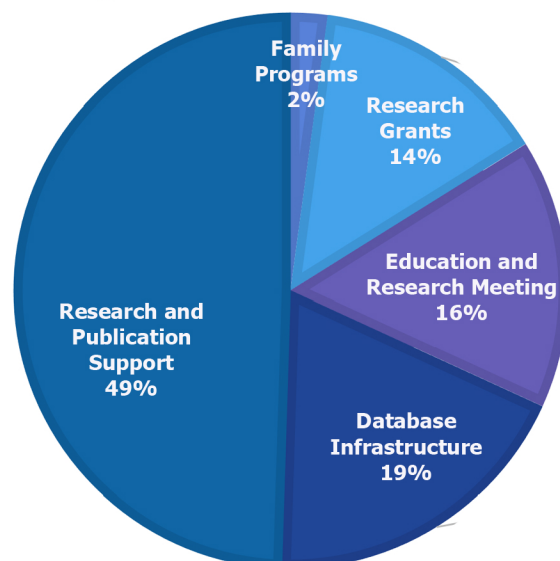
Thank you,

Michael Vitale, MD MPH

Expenses



Programs



Research Factory "Pipeline of Progress"



Identify the Problem:
27 investigators invited to
Research Factory

Develop Questions:
44 ideas debated,
discussed, refined; resulted
in 27 research questions

Analysis:
Data sent to lead
investigator for analysis

Database:
Queried database of 4,000
patients to obtain data



Peer Review:
Other investigators review results; make
suggestions to strengthen and clarify

Dissemination:
Publication submitted to
peer-reviewed journal and available
online for families



Presentation:
Lead investigator
presents at major
society meeting

Patient Care:
The ultimate goal -
**better outcomes for
our patients**

Presentation Highlight

Unplanned Return to OR for EOS Children: A Comprehensive Evaluation of all Diagnoses and Instrumentation Strategies.

Led by Dr. Jack Flynn from Children's Hospital of Philadelphia, the study reviews potential risk factors for surgical patients requiring unplanned additional surgeries due to complications. It was determined by reviewing 474 relevant patients in our database that all patients with growing instrumentation to treat early onset scoliosis have a 30% chance of unplanned additional surgeries. This study is continuing to build on past study group work to classify diagnoses. The study team used the data to highlight which diagnoses are more at risk. This was presented at ICEOS in San Diego California on November 17, 2017. This is part of a long list of studies from our Research Factory that are improving patient care through advancing knowledge.

Patient Spotlight

JaRieya, Age 13

I have juvenile idiopathic scoliosis, but I do not let my scoliosis define who I am. I accomplish many things and happen to have scoliosis too. My life's goal is to fulfill my love of studying cells and become a biologist. There never seems to be enough time in the day; mine are always filled with lip sync dancing, winning corn hole games with my mom, rocking out on my ukulele and studying math and French. Next I think I will master curling.

I have been seeing Dr. Jeffrey Sawyer at the Campbell Clinic for six years now. He is more than just my doctor; he is my friend. Dr. Sawyer says, the hardest thing about taking care of me is keeping up with all the things I have going on in my life. My testimony to other kids is that nothing is impossible; if you just believe and have faith in your heart, you can do anything.





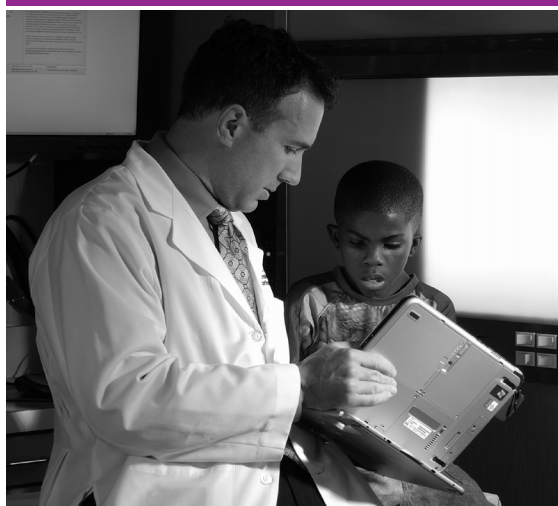
RESEARCH

The Children's Spine Study Group works to ensure quality research in current treatments. From VEPTR in years past to Magnetic Growing Rods and beyond, our clinicians use and study these groundbreaking treatments to better the lives of children all over the world.



MISSION

To help children with spine problems live longer, better lives.



FAMILY

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

Education is fundamental in the progress of treatments for spinal deformities. The Children's Spine Foundation enables international fellows to travel to our prestigious centers to be educated in modern patient care techniques.



Publications 2017

- Cyr M, St. Hilaire T, Thompson GH, Vitale MG, Garg S, Children's Spine Study Group, Growing Spine Study Group. (January 2017). Classification of Early Onset Scoliosis Has Excellent Inter and Intra Observer Reliability. *Journal of Pediatric Orthopedics*, 7(1):e1-e3. <https://www.ncbi.nlm.nih.gov/pubmed/26600295>
- DeFrancesco CJ, Flynn JM, Smith JT, Luhmann SJ, SawyervJR, Glotzbecker M, Pahys J, Garg S, Vitale MG, Farrington DM, Sturm P, Children's Spine Study Group. (December 1, 2017). Clinically apparent adverse reactions to intra-wound vancomycin powder in early onset scoliosis are rare. *Journal of Children's Orthopaedics*, 11(6):414-418. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5725766/>
- El-Hawary R, Kadim M, Vitale MG, Smith JT, Samdani A, Flynn JM, Children's Spine Study Group. (December 2017). VEPTR Implantation to Treat Children with Early Onset Scoliosis without Rib Abnormalities: A Prospective Multicenter Study. *Journal of Pediatric Orthopedics*, 37(8): e599-e605. [https://www.spine-deformity.org/article/S2212-134X\(17\)30343-X/fulltext](https://www.spine-deformity.org/article/S2212-134X(17)30343-X/fulltext)
- Glotzbecker M, St. Hilaire TA, Pawelek JB, Thompson GH, Vitale MG, Children's Spine Study Group, Growing Spine Study Group. (October 23, 2017). Best Practice Guidelines for Surgical Site Infection Prevention with Surgical Treatment of Early Onset Scoliosis. *Journal of Pediatric Orthopedics*, epub. https://journals.lww.com/pedorthopaedics/Abstract/publishahead/Best_Practice_Guidelines_for_Surgical_Site.98987.aspx
- Gomez JA, Grzywna A, Miller PE, Karlin LI, Garg S, Sanders JO, Sturm PF, Sponseller PD, D'Astous JL, Glotzbecker MP, Children's Spine Study Group, Growing Spine Study Group. (December 2017). Initial Cast Correction as a Predictor of Treatment Outcome Success for Infantile Idiopathic Scoliosis. *Journal of Pediatric Orthopedics*, 37(8): e625-e630. <https://www.ncbi.nlm.nih.gov/pubmed/28834850>
- LaGreca J, Flynn T, Cahill PJ, Samdani A, Vitale MG, El-Hawary R, Smith, JT, Phillips JH, Flynn JM, Glotzbecker M, Garg, S, Children's Spine Study Group. (December 2017). Patients without intraoperative neuromonitoring (IONM) alerts during VEPTR implantation did not sustain neurologic injury during subsequent routine expansions: a retrospective multi-center cohort study. *Journal of Pediatric Orthopedics*, 37(8): e619-e624. <https://www.ncbi.nlm.nih.gov/pubmed/28328563>
- Nossov SB, Curatolo E, Campbell RM, Mayer OH, Garg S, Cahill PJ, Children's Spine Study Group. (April 10, 2017). Are We Reducing Respiratory Assistance Requirements at Two Years? *Journal of Pediatric Orthopedics*, epub. [https://www.spine-deformity.org/article/S2212-134X\(15\)00272-5/fulltext](https://www.spine-deformity.org/article/S2212-134X(15)00272-5/fulltext)

Presentations 2017

- Anari J, Flynn JM, Vitale MG, Smith JT, Gomez JA, Children's Spine Study Group. (November 2017). Unplanned Return to OR for EOS Children: A Comprehensive Evaluation of all Diagnoses and Instrumentation Strategies. Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- Campbell RM, Smith JT, Garg S, Glotzbecker MP, Pahys JM, Samdani AF, Flynn JM, Mayer O, Cahill PJ. (September 2017). Worsening Assisted Ventilator Rating (AVR) Correlates with Decreased Scores on Early Onset Scoliosis Quality of Life (EOSQ) in Patients Treated with Rib-Based Growing Systems (RBGS): A Prospective Cohort Study. Poster Presented at the 52nd Meeting of the Scoliosis Research Society (SRS), Philadelphia, PA, USA.
- El Bromboly Y, Hurry J, Johnston C, McClung A, St. Hilaire T, Flynn T, Padhye K, Samdani A, Glotzbecker M, El-Hawary R, Children's Spine Study Group. (September 2017). Distraction-Based Surgeries Increase Spine Length for Patients with Non-Idiopathic Early Onset Scoliosis (EOS) - 5 Year Follow up. Poster Presented at the 52nd Meeting of the Scoliosis Research Society (SRS), Philadelphia, PA, USA.
- El Bromboly Y, Johnston C, McClung A, Samdani A, Glotzbecker M, St. Hilaire T, Hurry J, Padhye K, Flynn T, El-Hawary R, Children's Spine Study Group, Growing Spine Study Group. (November 2017). Does the Type of Proximal Anchor Used During Distraction-Based Surgeries for Patients with Non-Idiopathic EOS Affect Spine Length? Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- El Bromboly Y, Hurry J, Padhye K, Johnston C, McClung A, Samdani A, Glotzbecker M, St. Hilaire T, Flynn T, El-Hawary R, Growing Spine Study Group, Children's Spine Study Group. (November 2017). Distraction-Based Surgeries Increase Spine Length for Patients with Non-Idiopathic Early Onset Scoliosis (EOS). Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA."
- El-Hawary R, Morash K, Kadhim M, Vitale MG, Smith JT, Samdani A, Flynn JT, Children's Spine Study Group. (November 2017). VEPTR Treatment of Early Onset Scoliosis (EOS) in Children Without Rib Abnormalities: Long-Term Results of a Prospective, Multicenter Study. Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- Flynn JM, DeFrancesco C, Smith JT, Luhmann SJ, Sawyer JR, Glotzbecker MP, Pahys JM, Garg S, Vitale MG, Farrington DM, Sturm PF, Sanders JO, Morgan J, Sze C, Fournory JM, Davis EA, Children's Spine Study Group. (May 2017). Adverse Reactions to Intra-Wound Vancomycin Powder in Early Onset Scoliosis: A Multicenter Study of 1398 Children < 12 Years Old. Poster Presented at the Meeting of the Pediatric Orthopaedic Society of North America (POSNA) and the European Pediatric Orthopaedic Society (EPOS), Barcelona, Spain.
- Glotzbecker MP, Grzywna BA, Miller PE, Vitale MG, Sawyer JR, Pahys JM, Cahill PJ, Emans JB, Children's Spine Study Group. (September 2017). Hemoglobin Levels Pre- and Post-Treatment as a Surrogate for Disease Severity in Early Onset Scoliosis. Poster Presented at the 52nd Meeting of the Scoliosis Research Society (SRS), Philadelphia, PA, USA.
- Gomez JA, Kubat O, Hurry J, Soroceanu A, Flynn T, Tovar M, Hanstein R, Lafage V, Schwab F, Smith JT, Skaggs DL, El-Hawary R, Children's Spine Study Group, Growing Spine Study Group. (September 2017 & November 2017). Spinopelvic alignment affects Health-related Quality of Life (HRQoL) for Patients with Early Onset Scoliosis. Poster Presented at the Meeting of the Pediatric Orthopaedic Society of North America (POSNA) and the European Pediatric Orthopaedic Society (EPOS), Barcelona, Spain, & at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- Gupta P, Roye B, Sawyer J, Brassard F, El-Hawary R, Children's Spine Study Group. (November 2017). Magnetically Controlled Growing Rods: Sagittal Plane Analysis and the Risk of Proximal Junctional Kyphosis Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- Garg S, Smith JT, Michael N, St. Hilaire T, Palmer C, Cyr M, Morgan J, Heagy V, Children's Spine Study Group, Erickson M. (May 2017). Complication Severity Score for Growth-Friendly Surgery Has Very Strong Inter and Intra Observer Agreement. Poster Presented at the Meeting of the Pediatric Orthopaedic Society of North America (POSNA) and the European Pediatric Orthopaedic Society (EPOS), Barcelona, Spain.
- Kawakami N, Matsumoto H, Saito T, Tauchi R, Ohara T, Redding G. (November 2017). Pre-operative Six Minute Walk Performance in Children with Congenital Scoliosis. Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.



Presentations 2017 Continued

- Kawakami K, Saito T, Tauchi R, Ohara T, Kazuaki M, Yamauchi I, Kawakami N. (November 2017). Does Casting Have Negative Implications on Pulmonary Function in Early Onset Scoliosis? Evaluation of Pulse Oximetry in Pre- and Post Casting. Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- Kondratyeva A, Feinberg N, Bloom Z, Hung CW, Matsumoto H, Smith JT, Pahys JM, Garg S, Roye DP, Vitale M, Children's Spine Study Group. (July 2017 & September 2017). Proximal Rib-Based Constructs in Early Onset Scoliosis: Survivorship at or near Skeletal Maturity. Poster Presented at the 24th International Meeting on Advanced Spine Techniques (IMAST), Cape Town, South Africa, & at the 52nd Meeting of the Scoliosis Research Society (SRS), Philadelphia, PA, USA.
- Larson NA, St. Hilaire T, Pawelek J, Emans J, Skaggs D, Pahys J, Children's Spine Study Group, Growing Spine Study Group. (September 2017). Congenital Spine Deformity with Fused Ribs Treated with Proximal Rib- vs. Spine-Based Growing Constructs. Poster Presented at the 52nd Meeting of the Scoliosis Research Society (SRS), Philadelphia, PA, USA.
- Matsumoto H, Auran E, Hung CW, Sturm PF, Garg S, Sanders J, Oetgen M, Roye DP, Vitale MG, Children's Spine Study Group, Growing Spine Study Group. (September 2017). All that Glitters is Not Gold – Serial Casting for EOS Negatively Affects Health-Related Quality of Life even after Discontinuation of Serial Casting: A 2 Year Follow-up. Poster Presented at the 52nd Meeting of the Scoliosis Research Society (SRS), Philadelphia, PA, USA.
- Matsumoto H, Campbell M, Minkara A, Roye DP, Garg S, Johnston C, Samdani A, Smith JT, Sponseller P, Sturm PF, Vitale MG, Children's Spine Study Group, Growing Spine Study Group. (November 2017). Development of a Risk Severity Score (RSS) Predicting Surgical Site Infection in Early Onset Scoliosis: Identifying High-Risk Patients. Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- Matsumoto H, Feinberg N, Garg S, Sawyer J, Sturm PF, Roye B, Vitale MG, Children's Spine Study Group (December 2017). The Baseline Caregiver and Financial Burden Scores of EOS Patients are Significantly Lower than National Normative Scores Poster Presented at the 38th SICOT Orthopaedic World Congress, Cape Town, South Africa.
- Matsumoto H, Minkara A, Feinberg N, Smith J, Samdani A, Glotzbecker M, Sawyer JR, Skaggs D, Roye D, Vitale MG, Children's Spine Study Group, Growing Spine Study Group. (May 2017 & September 2017). Development of a Risk Severity Score Predicting Surgical Site Infection in Early Onset Scoliosis. Poster Presented at the Meeting of the Pediatric Orthopaedic Society of North America (POSNA) and the European Pediatric Orthopaedic Society (EPOS), Barcelona, Spain & at the 52nd Meeting of the Scoliosis Research Society (SRS), Philadelphia, PA, USA.
- Matsumoto H, Mueller JD, Minkara AA, Cahill PJ, Sturm PF, Smith JT, Thompson GH, Sponseller PD, Skaggs DL, Vitale MG, Roye DP, Growing Spine Study Group, Children's Spine Study Group. (May 2017 & September 2017). Improvement of Pulmonary Function Measured by Patient Reported Outcomes in Patients with Spinal Muscular Atrophy after VEPTR surgery. Poster Presented at the Meeting of the Pediatric Orthopaedic Society of North America (POSNA) and the European Pediatric Orthopaedic Society (EPOS), Barcelona, Spain & at the 52nd Meeting of the Scoliosis Research Society (SRS), Philadelphia, PA, USA.
- McClung AM, Mundis GM, Pawelek JB, Garg S, Yaszay B, Boachi-Adjei O, Sanders JO, Sponseller PD, Perez-Grueso FS, Lavelle W, Emans J, Johnston CE, Akbarnia BA, Children's Spine Study Group, Growing Spine Study Group. (November 2017). Utilization and Reliability of Intraoperative Neuromonitoring in Vertebral Column Resections for Severe Early-Onset Scoliosis. Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- Minkara A, Flynn JM, Matsumoto H, Glotzbecker MP, Smith JT, Samdani A, Saiman L, Vitale M, Children's Spine Study Group. (September 2017 & November 2017). Building the Case for Optimal Prophylaxis for Growth-Friendly Surgery for Non-idiopathic Scoliosis: Using Vancomycin and Aminoglycosides. Poster Presented at the 52nd Meeting of the Scoliosis Research Society (SRS), Philadelphia, PA, USA, & at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- Minkara AA, Vitale MG, Matsumoto H, Glotzbecker MP, Flynn JM, Smith JT, Samdani AF, Saiman L, Children's Spine Study Group. (September 2017 & December 2017). Deep Surgical Site Infections (SSIs) Following Growth-Friendly Procedures in Children with Non-Idiopathic Scoliosis Requiring Repetitive Surgery: Per Patient Risk 6-Fold Higher than Per Procedure Risk. Poster Presented at the 52nd Meeting of the Scoliosis Research Society (SRS), Philadelphia, PA, USA, & at the 38th SICOT Orthopaedic World Congress, Cape Town, South Africa.
- Pedersen PH, Xavier F, Vergari C, Skalli W, Eiskjaer SP, Vialle R. (November 2017). Nano-Dose Protocol for 3D Reconstruction of the Spine in Early Onset Scoliosis: Preliminary Results of a Phantom Based and Clinically Validated Study using Stereo-Radiography. Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.

Presentations 2017 Continued

- Ramirez-Lluch NF, Olivella G, Rodriguez O, Marrero P, Garg S, Smith JT, Vitale MG, Betz RR, Children's Spine Study Group. (June 2017 & September 2017). Spasticity is a Risk factor of Complications and Surgical Outcome in the Management of Neuromuscular Early-Onset Scoliosis (EOS) with a Rib-Based Growing System (RBGS). Poster Presented at the 15th Annual International Phillip Zorab Symposium, London, UK, & at the 52nd Meeting of the Scoliosis Research Society (SRS), Philadelphia, PA, USA.
- Redding G, Ho M, Bompadre V, White K, Krengel W, Chen M. (November 2017). Referral Patterns and Sleep Abnormalities Among Children with EOS. Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- Roye B, Hung CW, Matsumoto H, Campbell M, Roye DP, Vitale M. (November 2017). Comparison of Complications and Unplanned OR Visits between Magnetically Controlled Growing Rods and Vertical Expandable Prosthetic Titanium Rib. Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- Santana GO, Ramirez-Lluch N, Rodriguez O, Marrero P, Vitale M, Smith J, Garg S, Betz RR, Children's Spine Study Group. (November 2017). Spasticity is a Risk factor of Complications and Surgical Outcome in the Management of Early-Onset Neuromuscular Scoliosis with a Rib-Based Growing System. Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- Sawyer JR, Hung CW, Bloom Z, Matsumoto H, Smith JT, Phillips J, Sturm PF, Sanders JO, Viral JV, Ramo BA, Vitale MG, Growing Spine Study Group, Children's Spine Study Group. (September 2017). Conversion of Traditional Growth Friendly Instrumentation to Magnetically Controlled Growth Rods Does Not Affect Radiographic Outcomes nor Increase Hardware Related Complications at Two Years Follow Up. Poster Presented at the 52nd Meeting of the Scoliosis Research Society (SRS), Philadelphia, PA, USA.
- Sawyer JR, Hung CW, Bloom Z, Matsumoto H, Smith JT, Phillips J, Sturm PF, Vitale MG, Children's Spine Study Group. (May 2017). Expect Minimal Further Correction and Higher Risk of Complications in Revision from Traditional Growth Rods to Magnetically Controlled Growing Rods. Poster Presented at the Meeting of the Pediatric Orthopaedic Society of North America (POSNA) and the European Pediatric Orthopaedic Society (EPOS), Barcelona, Spain.
- Schur MD, Andras LM, Gonsalves NR, Sponseller PD, Emans JB, Vitale MG, Skaggs DL, Children's Spine Study Group, Growing Spine Study Group. (September 2017). Pelvic Obliquity Correction in Distraction-Based Growth Friendly Implants. Poster Presented at the 52nd Meeting of the Scoliosis Research Society (SRS), Philadelphia, PA, USA.
- Skaggs DL, Akbarnia BA, Pawelek J, Matsumoto H, St. Hilaire T, Sturm PF, Perez-Grueso FJS, Luhmann SJ, Sponseller PD, Smith JT, White KK, Vitale MG, Children's Spine Study Group, Growing Spine Study Group. (July 2017). Magnetically-Controlled Growing Rod Patients Have Better HRQOL Measures Compared to Traditional Growing Rod Patients A Multicenter Pilot Study. Poster Presented at the 24th International Meeting on Advanced Spine Techniques (IMAST), Cape Town, South Africa.
- Skaggs DL, Akbarnia BA, Pawelek J, Matsumoto H, St. Hilaire T, Sturm PF, Perez-Grueso FJS, Luhmann SJ, Sponseller PD, Smith JT, White KK, Vitale MG, Children's Spine Study Group, Growing Spine Study Group. (November 2017). Two Year HRQOL Measures are Similar Between Magnetically-Controlled Growing Rod Patients and Traditional Growing Rod Patients. Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- Welborn MC. (November 2017). Distortion of length measurements on digital images. Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- Welborn M, Degan T, D'Amato C, Krajchich JJ. (November 2017). Magnetic Spinal Growth Rods (MCGR) with and without Preoperative Traction for the Treatment of Severe Scoliosis. Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- White K, Bompadre V, Ramiez N, Varakitsomboon S, Garg S, Redding G, Krengel W, Children's Spine Study Group. (November 2017). Classification of Early Onset Scoliosis (C-EOS) and Pulmonary Function Outcomes. Poster Presented at the 11th International Congress on Early Onset Scoliosis (ICEOS), San Diego, CA, USA.
- Woon R, Andras LM, Noordeen HH, Morris S, Hutchinson J, Shah SA, Pawelek J, Johnston CE, Skaggs DL, Children's Spine Study Group, Growing Spine Study Group. (September 2017). Surgeon Survey Shows No Adverse Events with MRI in Patients with Magnetically Controlled Growing Rods (MCGR). Poster Presented at the 52nd Meeting of the Scoliosis Research Society (SRS), Philadelphia, PA, USA, & at the American Academy of Pediatrics (AAP) National Conference & Exhibition, Chicago, IL, USA.





Thank You

The Children's Spine Foundation is committed to making continued progress in research and education to improve the quality of life for patients with early onset scoliosis. This progress is only possible with your help. Your donation funds lifesaving research and provides information and support to patients and families throughout their journey. The Children's Spine Foundation is a 501(c)(3) non-profit foundation which relies solely on donations to pursue our mission.

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