



# 2018

## Annual Report



CHILDREN'S  
**SPINE**  
FOUNDATION®

# President's Message



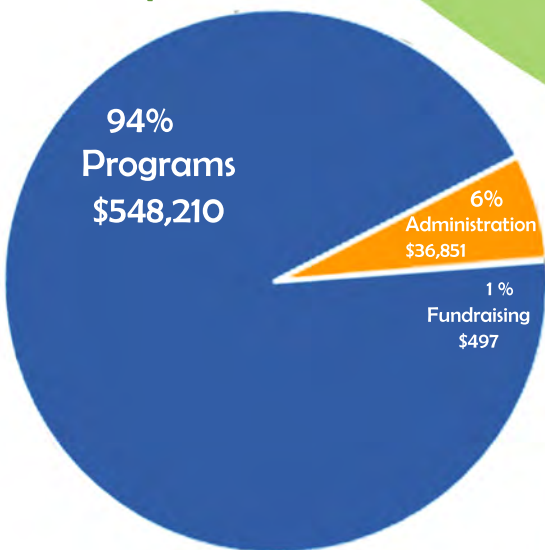
Reflection is an important part of any meaningful endeavor. Since our creation in 2002, the Children's Spine Study Group and Foundation has accomplished far beyond what a few investigators could dream of. We now have 55 investigators at 34 institutions. The study group has created and grown a Registry of over 5,000 early onset scoliosis patients. We have initiated educational programs for international fellows and physicians, assisted families to necessary medical care and improved the lives of children with spinal problems all over the globe.

Reviewing the past can help to shape a better future. This analysis gives us to the opportunity to imagine what could be possible. We are excited for the many purposeful possibilities to come!

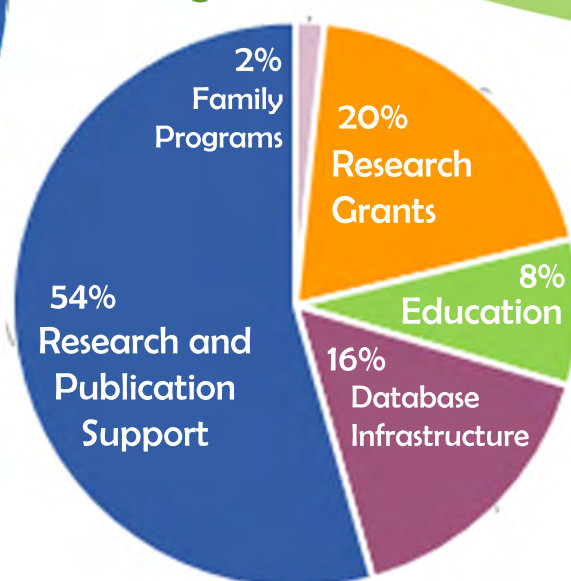
A handwritten signature in white ink, appearing to read "Michael Vitale".

Michael G. Vitale, MD, MPH

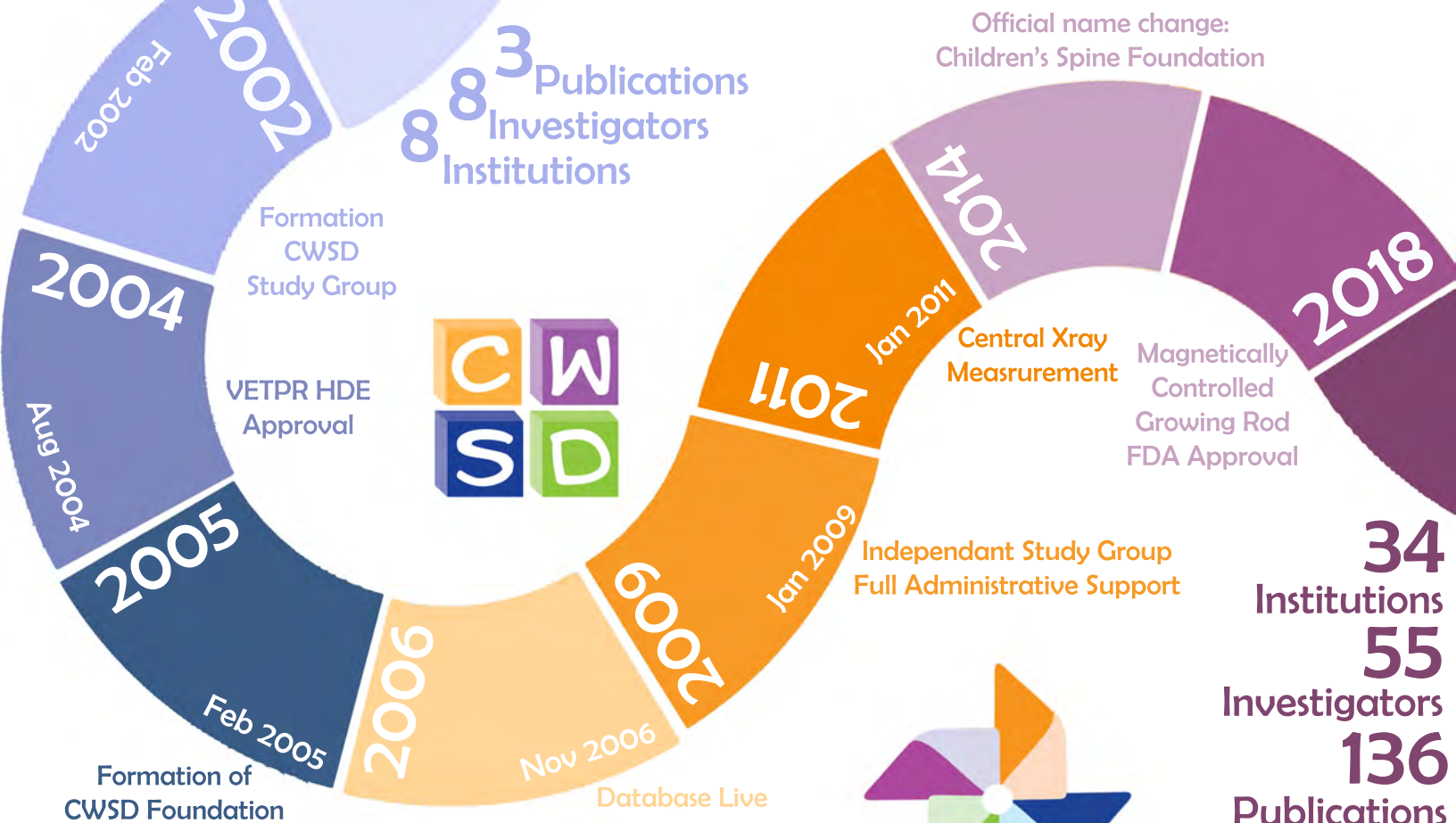
## Expenses



## Programs



## Financials



## A Look Back to Look Forward



For Braydon, life has always been just like everyone else's, as long as he was not at the hospital for surgery. Beginning at 6 years old, his chest wall needed support because his lungs did not have enough room. That support came when Dr. Bob Campbell and Dr. John Smith began treating him with a Vertical Expandable Prosthetic Titanium Rib (VEPTR) device to help him breathe easier. He was one of the first to receive this lifesaving

treatment. Since then he has undergone 41 surgeries. At

17, Dr. Smith corrected and fused his spinal deformity.

At 24, he does not have time to think about how he has gotten here; he is too busy at the airfield. Braydon considers himself a casual aviator, but professionally he prepares planes to fly every day, including his favorite medevacs and helicopters.

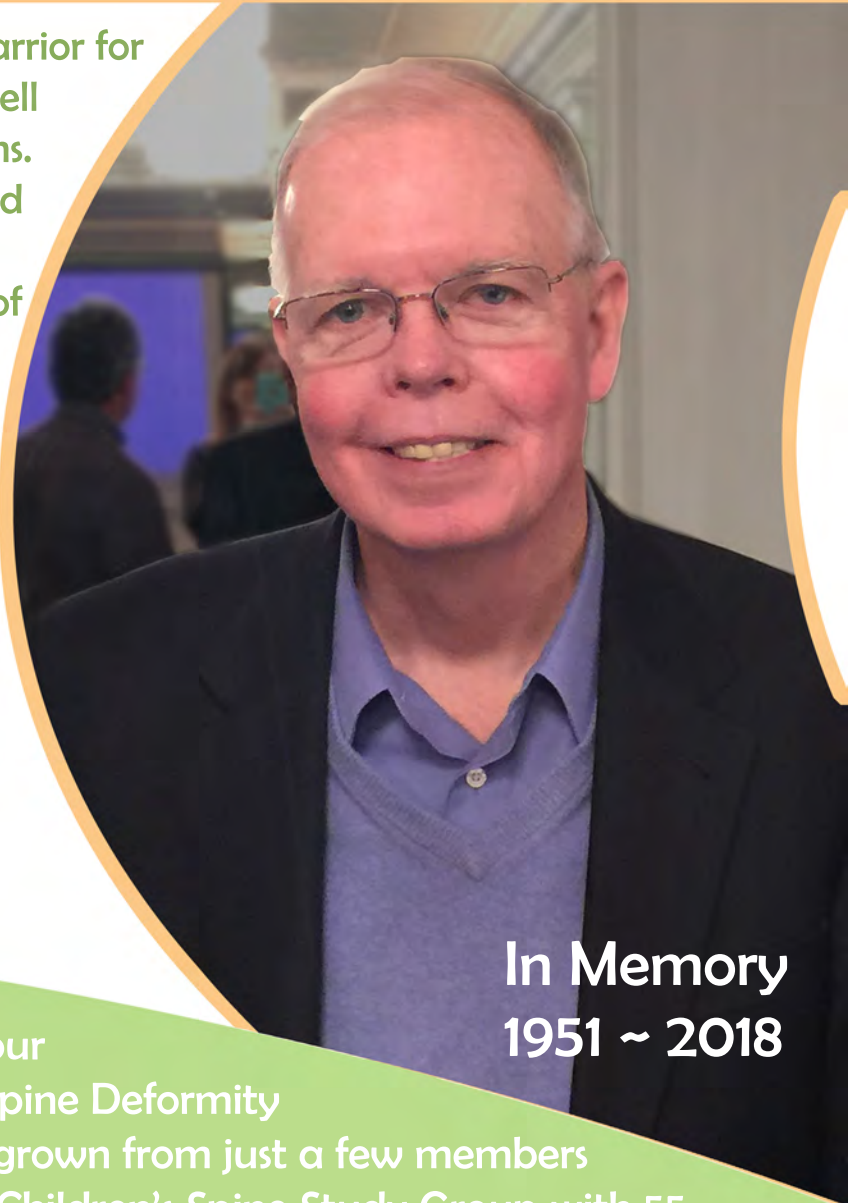
Because of his treatments, Braydon can fly anywhere and enjoy the natural beauty around him through his other love of photography. What would life be like without aviation, and all the things he loves? Luckily for Braydon, he never has to find out.

Catching up with Braydon



Dr. Robert Campbell was a true warrior for his family and patients. Dr. Campbell fought for those who had no options. He was an innovator, a teacher and understood the importance of working as a team. As a member of the original Chest Wall and Spine Deformity Executive Committee he exemplified our mission. We will continue his work with new programs and initiatives aimed at improving the approach of caring, training future providers and expanding our research.

Thank you Dr. Campbell for inspiring us all!



**In Memory**  
**1951 ~ 2018**

Many things may have changed through the years, but our mission has not. The Chest Wall Spine Deformity

Study Group has grown from just a few members

to the Children's Spine Study Group with 55 members. To improve a child's life is at the

center of what we strive for. While much of our research is focused on the efficacy of new technology, we also have devoted substantial resources to improving quality of treatment, quantifying patient quality of life and looking closely at long-term outcomes.



**Looking Forward**

Dedication

Collaboration

Leadership



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



Since 2002, The Children's Spine Study Group and Foundation have endeavored to accomplish our mission of helping children with spine problems lead longer, better lives. Since our inception, the landscape of treatments for these complex deformities has transformed dramatically. We are thrilled to be leading, creating, and studying this change.



# Academic Productivity

## 2018 Publications

Bachabi M, McClung A, Pawelek JB, El Hawary R, Thompson GH, Smith JT, Vitale MG, Akbarnia BA, Sponseller PD, Children's Spine Study Group, Growing Spine Study Group. (2018 June 8). Idiopathic Early-Onset Scoliosis: Growing Rods vs. Vertically Expandable Prosthetic Titanium Ribs at 5-Year Follow-Up. *JPO* epub.

Connell B, Oore J, Pahys J, Thompson G, St. Hilaire T, Flynn T, El-Hawary R, Children's Spine Study Group, Growing Spine Study Group. (2018 May - June). Growth Friendly Surgery is Effective at Treating Early Onset Scoliosis Associated with Goldenhar Syndrome. *Spine Deformity* 6(3): 327-333.

Eby SF, Hilaire TS, Glotzbecker M, Smith JT, White KK, Larson AN, Children's Spine Study Group. (2018 Aug 1). Thoracogenic Spinal Deformity: A Rare Cause of Early Onset Scoliosis. *JNS Spine* 12(4):406-412.

Feinberg N, Matsumoto H, Hung CW, St. Hilaire T, Pawelek J, Sawyer JF, Akbarnia B, Skaggs D, Roye BD, Roye D, Vitale MG. (2018 May - June). Expert Consensus and Equipose: Planning a Randomized Control Trial of Magnetically Controlled Growing Rods. *Spine Deformity* 6(3):303-307.

Grzywna A, McClung A, Sanders J, Sturm P, Karlin L, Glotzbecker M, Children's Spine Study Group, Growing Spine Study Group. (2018 Aug 1). Survey to Measure Variability in Early Onset Scoliosis Cast Practices. *JCO* 12(4):406-412.

Heflin J, Welborn M, Ramirez-Lluch N, Iriarte I, El-Hawary R, Fedorak GT, Smith JT, Children's Spine Study Group. (2018 Jul 15). Parallel Proximal Fixation In Rib-Based Growing Rod System: A Novel Approach To Deal With Proximal Anchor Migration. *Spine* 43(14):E855-E858.

Matsumoto H, Williams B, Park HY, Yoshimachi JY, Roye BD, Roye DP Jr, Akbarnia BA, Emans J, Skaggs D, Smith JT, Vitale MG. (2018 March). The Final 24-Item Early Onset Scoliosis Questionnaires (EOSQ-24): Validity, Reliability and Responsiveness. *Journal of Pediatric Orthopaedics* 38(3):144-151.

Michael N, Palmer C, Smith JT, Pan Z, St Hilaire T, Morgan J, Heagy V, Garg, S, Children's Spine Study Group. (2018 Apr). Complication Severity Score for Growth-Friendly Surgery Has Strong Inter-rater and Intra-rater Agreement. *JPO* 38(4): e190-e193.

Ramírez N, Valentín P, Mayer OH, Redding GJ, Rodríguez F, Vélez A, Jaume F, Iriarte I, Olivella G. (2018 September 24). The Spinal Structure and Lung Function Relationship in an Untreated Nonambulatory Myelomeningocele Group of Patients. *J AAOS* Epub.

Ramírez-Lluch N, Acevedo-Echevarría JM. (2018). Deformidad de la caja torácica. *Rev Chil Cir* 70(4):373-381.

Striano BM, Refakis C, Garg S, El-Hawary R, Pahys JM, Vitale M, Campbell RM, Flynn JM, Cahill PJ. (2018 Jul- Aug). How Often Do You Lengthen? A Physician Survey on Lengthening Practice for Prosthetic Rib Devices. *Spine Deformity* 6(4): 473-477.

White KK, Bompadre V, Shah SA, Redding GJ, Kregel WF 3rd, Mackenzie WG, Children's Spine Study Group, Growing Spine Study Group. (2018 July-Aug). Early Onset Spinal Deformity in Skeletal Dysplasias: A Multi-Center Study of Growth Friendly Systems. *Spine Deformity* 6(4):478-482.

Woon RP, Andras LM, Noordeen H, Morris S, Hutchinson J, Shah S, Pawelek J, Johnston C, Skaggs DL, Children's Spine Study Group, Growing Spine Study Group. (2018 May-Jun). Surgeon Survey Shows No Adverse Events with MRI in Patients with Magnetically Controlled Growing Rods (MCGR). *Spine Deformity* 6(3):299-302.

## 2018 Presentations

Adams A, Garg S, Anari J, Sturm PF, Pahys J, Murphy R, Flynn J, Children's Spine Study Group, & Cahill P. (November 2018). Does Serial Casting Under General Anesthesia for Infantile Idiopathic Scoliosis Affect Childhood Behavior? A Prospective Investigation in Response to the New FDA Warning. Poster Presented at The 12th International Congress on Early Onset Scoliosis (ICEOS), Lisbon, Portugal.

Anari J, Flynn JM, Cahill P, Vitale MG, Smith JT, Gomez J, Garg S, Baldwin K, & Children's Spine Study Group. (October 2018). Unplanned Return to OR (UPROR) for EOS Children: A Comprehensive Evaluation of all Diagnoses and Instrumentation Strategies. Poster Presented at The 53rd Annual Meeting & Course of the Scoliosis Research Society (SRS), Bologna, Italy.

Anari JB, Cahill P, Vitale MG, Smith JT, Gomez J, Keith Baldwin K, & Flynn J. (May 2018). Unplanned Return to OR for EOS Children: A Comprehensive Evaluation of all Diagnoses and Instrumentation Strategies. Poster Presented at The Pediatric Orthopaedic Surgeons of North America Annual Meeting (POSNA), Austin, Texas, USA.

Campbell M, Matsumoto H, Brown C, Callejo F, Roye DP, Roye BD, Larson AN, Vitale MG, & Children's Spine Study Group. (March 2018). 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 Annual Meeting (AAOS), New Orleans, Louisiana, USA.

Elbromboly Y, McClung A, Hurry J, Flynn T, Johnston C, Samdani A, Glotzbecker M, Children's Spine Study Group, El-Hawary R, St. Hilaire, & Growing Spine Study Group. (November 2018). Can Distraction-Based Surgeries Achieve Minimum 18 cm Thoracic Height for Patients with Early Onset Scoliosis? Poster Presented at The 12th International Congress on Early Onset Scoliosis (ICEOS), Lisbon, Portugal.

El-Hawary R, Morash K, Kadhim M, Vitale MG, Smith JT, Samdani A, Flynn J, & Children's Spine Study Group. (May 2018). VEPTR Treatment of Early Onset Scoliosis (EOS) in Children Without Rib Abnormalities: Long-Term Results of a Prospective, Multicenter Study. Poster Presented at The Pediatric Orthopaedic Surgeons of North America Annual Meeting (POSNA), Austin, Texas, USA.

Gomez J, Hanstein R, Anari J, Cahill P, Vitale MG, & Flynn JM. (October 2018). Risks for Revision in Growth Friendly Treatment For Early Onset Scoliosis (EOS). Poster Presented at The 53rd Annual Meeting & Course of the Scoliosis Research Society (SRS), Bologna, Italy.

Gomez J, Hanstein R, Schulz J, St. Hilaire T, White KK, El-Hawary R, Garg S, Cahill P, Vitale M, & Redding G. (May & November 2018). Comparison of deformity correction and complications with growth-friendly and early primary posterior spinal fusion in 8-11 year old children with scoliosis. Poster Presented at The Pediatric Orthopaedic Surgeons of North America Annual Meeting (POSNA), Austin, Texas, USA, and The American Academy of Pediatrics 2018 Conference and Exhibition (AAP), Orlando, Florida, USA.

Gomez J, Xin R, Lo Y, Hanstein R, St. Hilaire T, Flynn T, White K, El-Hawary R, Garg S, Cahill P, Vitale MG, & Redding G. (November 2018). Single Fusion (PSF) Vs Growth Friendly (GF) Device in Older EOS Patients. Poster Presented at The 12th International Congress on Early Onset Scoliosis (ICEOS), Lisbon, Portugal.

Gupta P, Morash K, Brassard F, Schottler J, January A, El-Hawary R, Roye BD, Hammerberg K, Sawyer J, & Children's Spine Study Group. (November 2018). Magnetically Controlled Growing Rods: Sagittal Plane Analysis and the Risk of Proximal Junctional Kyphosis. Poster Presented at The 12th International Congress on Early Onset Scoliosis (ICEOS), Lisbon, Portugal.



## 2018 Presentations Continued

Gupta P, Schottler J, January A, Brassard F, Morash K, El-Hawary R, Roye BD, Sawyer J, Hammerberg KW, & Children's Spine Study Group. (July 2018). Magnetically Controlled Growing Rods: Sagittal Plane Analysis and the Risk of Proximal Junctional Kyphosis. Poster Presented at The 25th International Meeting on Advanced Spine Techniques (IMAST), Los Angeles, California, USA.

Hosseini P, Akbarnia B, Tran S, Zhang J, Pawelek J, Johnston C, Shah S, Emans J, Mundis G, Yaszay B, Samdani AF, Sturm PF, Children's Spine Study Group, & Growing Spine Study Group. (October 2018). Does Rod Orientation and Use of Cross Connector Affect Spinal Height in Magnetically Controlled Growing Rod Patients? Poster Presented at The 53rd Annual Meeting & Course of the Scoliosis Research Society (SRS), Bologna, Italy.

Kawakami N, Matsumoto H, Toshiki S, Tauchi R, Ohara T, Redding G, & Children's Spine Study Group. (October & November 2018). Improvement of Function Outcome Using 6-minute walk in Patients with Congenital Scoliosis Treated by Growth Friendly Surgery; Five Years Follow-up Study. Poster Presented at The 53rd Annual Meeting & Course of the Scoliosis Research Society (SRS), Bologna, Italy, & The 12th International Congress on Early Onset Scoliosis (ICEOS), Lisbon, Portugal.

Larson AN, Baký F, St. Hilaire T, Pawelek J, Skaggs D, Emans J, Pahys JM, Children's Spine Study Group, & Growing Spine Study Group. (October 2018). Impact of Expansion Thoracostomy on Patients with Scoliosis and Fused Ribs Treated with Rib-Based Growing Constructs. Poster Presented at The 53rd Annual Meeting & Course of the Scoliosis Research Society (SRS), Bologna, Italy.

Matsumoto H, Roye DP, Redding G, Marciano G, Ha J, White KK, Children's Spine Study Group, & Growing Spine Study Group. (November 2018). Subjective Health Related Quality of Life (HRQoL) Outcomes are Different from Objective Pulmonary Function Testing. Poster Presented at The 12th International Congress on Early Onset Scoliosis (ICEOS), Lisbon, Portugal.

McClung A, Mundis GM, Pawelek J, Garg S, Yaszay B, Boachie-Adjei O, Sanders JO, Sponseller P, Perez-Gruoso FJS, Lavelle WF, Emans JB, Johnston CE, Akbarnia BA, Children's Spine Study Group, & Growing Spine Study Group. (October 2018). Vertebral Column Resection for Early-Onset Scoliosis: Indications, Utilization and Outcomes. Poster Presented at The 53rd Annual Meeting & Course of the Scoliosis Research Society (SRS), Bologna, Italy.

McClung A, Williams BA, Blakemore LC, Shah SA, Pawelek J, Sponseller PD, Parent S, Emans JB, Sturm PF, Yaszay B, Akbarnia BA, & Growing Spine Study Group. (November 2018). Spinal MRI Utilization in Patients with Early-Onset Scoliosis - Review of a Large Multi-Center Database. Poster Presented at The 12th International Congress on Early Onset Scoliosis (ICEOS), Lisbon, Portugal.

Minkara A, Matsumoto H, Glotzbecker M, Flynn J, Smith J, Samdani A, Saiman L, Vitale M, & Children's Spine Study Group. (May 2018). Building the Case for Optimal Prophylaxis for Growth-Friendly Surgery for Non-idiopathic Scoliosis: Using Vancomycin and Aminoglycosides. Poster Presented at The Pediatric Orthopaedic Surgeons of North America Annual Meeting (POSNA), Austin, Texas, USA.

Murgai RR, Schur MD, Andras LM, Gonsalves NR, Sponseller PD, Emans JB, Vitale MG, Skaggs DL, Growing Spine Study Group, & Children's Spine Study Group. (November 2018). Pelvic Screw Fixation Maintains Lumbar Lordosis in Growing Rod Constructs Better Than S Hooks. Poster Presented at The 12th International Congress on Early Onset Scoliosis (ICEOS), Lisbon, Portugal.

## 2018 Presentations Continued

Murphy R, Pahys J, Garg S, Barfield W, St. Hilaire T, Emans J, Samdani A, Smith JT, & Sawyer J. (November 2018). Surgeon Indications for Discontinuation of a Lengthening Program for Early Onset Scoliosis. Poster Presented at The 12th International Congress on Early Onset Scoliosis (ICEOS), Lisbon, Portugal.

Nazareth A, Hosseini P, Skaggs DL, Akbarnia BA, Johnston CE, Shah SA, Emans JB, Mundis GM, Yaszay B, Sturm PF, Andras LM, & Growing Spine Study Group. (November 2018). Differential Lengthening of MCGR Does Not Change Coronal Balance or Rod Length. Poster Presented at The 12th International Congress on Early Onset Scoliosis (ICEOS), Lisbon, Portugal.

Ramirez N, Olivella G, Rodriguez O, Marrero P, Smith JT, Garg S, Vitlae M, Betz R, & Children's Spine Study Group. (November 2018). Repeated lengthening of rib to pelvis distraction devices in patients with Neuromuscular Early Onset Scoliosis do not improve spinal alignment after initial implant. Poster Presented at The 12th International Congress on Early Onset Scoliosis (ICEOS), Lisbon, Portugal.

Redding G, Bompadre V, Waldhausen J, Kregel W, & White KK. (November 2018). Pre-Operative Lung Function in Children with EOS. Poster Presented at The 12th International Congress on Early Onset Scoliosis (ICEOS), Lisbon, Portugal.

Roye B, Campbell M, Matsumoto H, Gbolo FC, Roye DP, El-Hawary R, Gupta P, Sawyer JR, White KK, Smith JT, Vitale MG, Children's Spine Study Group. (November 2018). Smaller Rods in Magnetically Controlled Growing Rods are at Increased Risk of Fracture after 3 Years. Poster Presented at The American Academy of Pediatrics 2018 Conference and Exhibition, New Orleans, Louisiana, USA.

Roye BD, Campbell M, Matsumoto H, Pahys JM, Welborn M, Sawyer JR, Fletcher ND, McIntosh AL, Sturm PF, Gomez JA, Lenke LG, Vitale MG, & Children's Spine Study Group. (November 2018). Consensus-Based Best Practice Guidelines (BPG) for Use of Halo Gravity Traction (HGT) for Pediatric Spinal Deformity. Poster Presented at The 12th International Congress on Early Onset Scoliosis (ICEOS), Lisbon, Portugal.

Samdani AF, Pahys JM, Smith JT, Samuel S, Vitale MG, El-Hawary R, Flynn JM, Sawyer J, Betz RR, Hwang S, & Children's Spine Study Group. (October 2018). Magnetic Growing Rods in the Treatment of Nonambulatory Neuromuscular Scoliosis: How Do They Compare to Traditional Growing Systems? Poster Presented at The 53rd Annual Meeting & Course of the Scoliosis Research Society (SRS), Bologna, Italy.

Schulz J, Kubat O, Hurry J, Soroceanu A, Flynn T, Tovar M, Hanstein R, Lafage V, Schwab F, Smith JT, Skaggs D, & El-Hawary R. (May 2018). Spinopelvic alignment affects Health-related Quality of Life (HRQoL) for Patients with Early Onset Scoliosis. Poster Presented at The Pediatric Orthopaedic Surgeons of North America Annual Meeting (POSNA), Austin, Texas, USA.

Siddiqui A, Nazareth A, Andras LM, Gupta P, Vitale MG, Smith JT, & Skaggs DL. (November 2018). 18% of EOS patients Treated with MCGR have Minimal Lengthening Episodes Resulting in <1mm of Distraction. Poster Presented at The 12th International Congress on Early Onset Scoliosis (ICEOS), Lisbon, Portugal.

Skaggs DL, Schur MD, Andras LM, Gonsalves N, Sponseller PD, Emans JB, Vitale MG, Growing Spine Study Group, & Children's Spine Study Group. (March 2018). Pelvic Obliquity Correction in Distraction-Based Growth Friendly Implants. Poster Presented at The American Academy of Orthopaedic Surgeons Annual Meeting (AAOS), New Orleans, Louisiana, USA.

White KK, Bompadre V, Redding G, Garg S, Ramirez-Lluch NF, Varakitsomboon S, & Kregel WF. (March 2018). Classification of Early Onset Scoliosis (C-EOS) and Pulmonary Function Outcomes. Poster Presented at The American Academy of Orthopaedic Surgeons Annual Meeting (AAOS), New Orleans, Louisiana, USA.



# Leadership

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Thank you

On behalf  
of our 5000  
patients, thank  
you for your  
continued support.  
Together we can  
improve the lives of  
children living with  
complex spine deformity.



[www.ChildrensSpineFoundation.org](http://www.ChildrensSpineFoundation.org)

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## Special Recognition

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