

Annual

**Pediatric Spine
Foundation**

2022



Report

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A MESSAGE FROM OUR PRESIDENT

Dr. Jack Flynn
Children's Hospital of Philadelphia



2022 was truly a positive, transformational year for the Pediatric Spine Foundation—a fact obvious to anyone who attended the 16th Annual International Congress on Early Onset Scoliosis (ICEOS) in Rome this year. For the past five years, we have worked to unite our two legacy study groups, and to make ICEOS the must-attend meeting for all who care for children with complex spine deformities. In Rome, we began with a highly productive PSSG Research Factory, brilliantly led by Michael Glotzbecker. The world's thought-leaders in pediatric spine brainstormed for several hours to launch studies critically assessing our current care and working towards better treatments and outcomes in the future. The formation of Research Interest Groups has accelerated the progress of our work, and limited conflicts and overlaps between studies. With 186 members spanning 12 countries, the PSSG researchers benefit from 82 active sites enrolling patients, and a database of 11,300 unique patients/118,300 patient evaluations/181,000 radiographs. This is the world's biggest spine database; the complex, heterogeneous spine deformities we study require this level of size and sophistication. After the Research Factory, 146 pediatric orthopaedists, neurosurgeons, pulmonologists, and researchers from 26 nations gathered for ICEOS 2022. Planned and led perfectly by Burt Yaszay, ICEOS was a forum to share innovations, complex cases, research study results and the seasoned perspectives of the founders of our specialty. For many of us, ICEOS is the most interactive, collaborative conference we attend. Everyone learns, and heads home informed to better care for their patients. It takes substantial resources for Tricia St. Hilaire and her team to continue driving our work forward. We are so grateful to those PSSG members, PSF philanthropists and Industry Partners who contribute generously. With the combination of thought-leaders, generous contributors and world-class research infrastructure and management, the Pediatric Spine Foundation is positioned to further improve the lives of children around the world challenged with complex spine problems. PSF is proud, but not satisfied. The best is yet to come.



THE POWER OF COUNCIL

Dr. Amer Samdani
Research Council Chair

The Pediatric Spine Study Group is a dynamic, motivated group of diverse clinician members who dedicate countless resources to produce quality research aimed at improving the lives of patients with complex spine deformity. The PSSG Research Council was created with the primary goal to establish, facilitate, and support member research from development to publication. The Research Council is comprised of 10 members, each with diverse specialties and research backgrounds. This past year, the Research Council has reviewed over 55 proposals and our focus has been on how to improve the research process and expand resources to our members. It is imperative our research remain focused on current trends and it is to that end there has been considerable recent efforts devoted to anterior vertebral body tethering research. This past year we formulated over 58 projects. We were also able to present 28 projects at national meetings. Simi-



Josh Pahys

Shriners Hospital for Children Philadelphia



Josh Murphy

Children's Healthcare of Atlanta



Ying Li

C.S. Mott Children's Hospital



Noelle Larson

Mayo Clinic



Benjamin Roye

Children's Hospital of New York-Presbyterian



Chris Hardesty

Rainbow Babies Children's Hospital



Rob Murphy

Medical University of South Carolina



Jaime Gomez

Children's Hospital at Montefiore



Lindsay Andras

Children's Hospital of Los Angeles



Matthew Oetgen

Children's National Hospital

larly, understanding the pros and cons of magnetic growing systems remains a research focus as does measuring the impact of intervention on quality of life as measured by the EOSQ. The Research Council conducts many other activities to further the research process. Statistical guidance and support facilitates optimal study design and methodol-

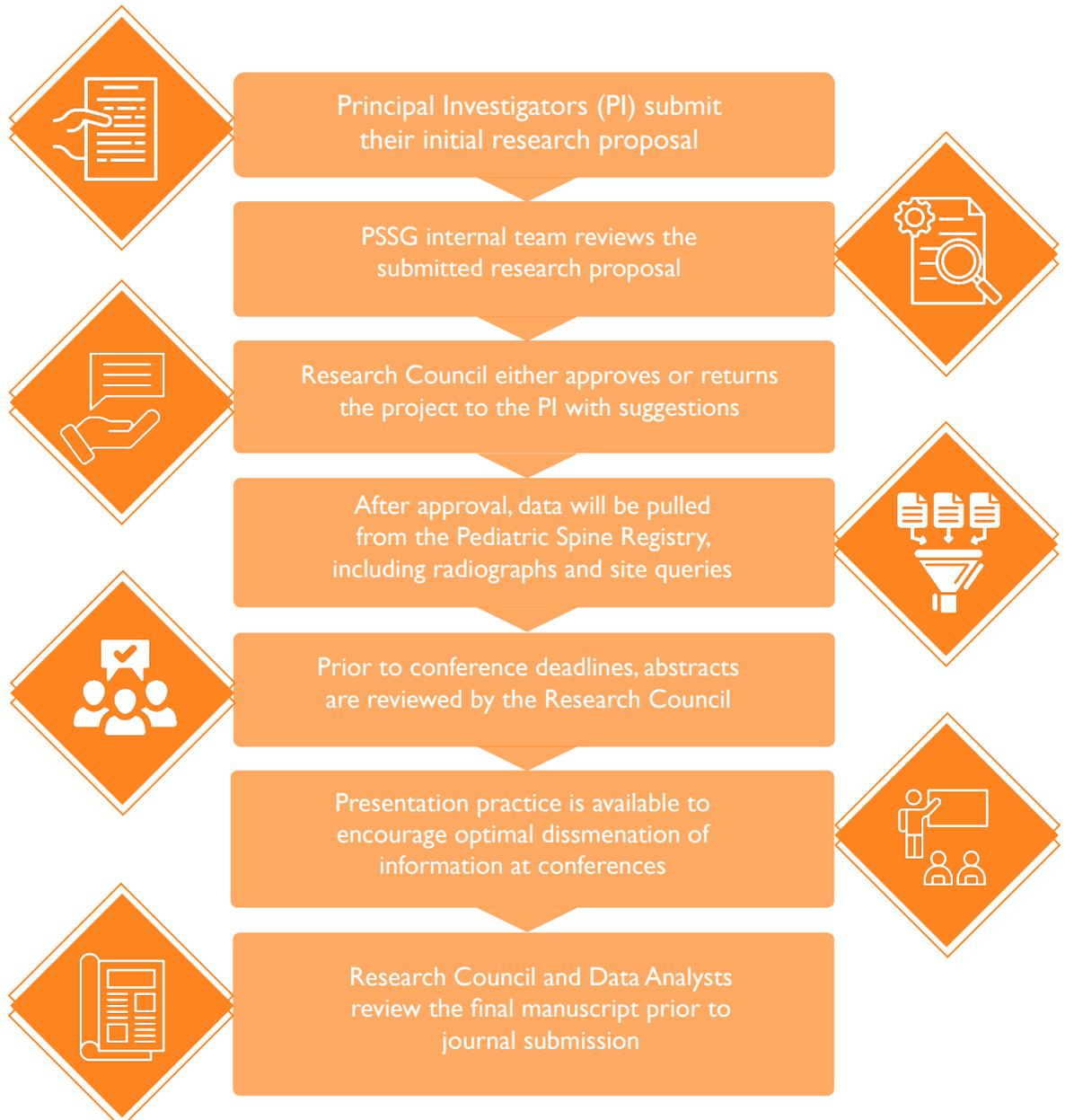
58 active studies

◀ **2022** ▶

33 papers published

ogy. All abstracts undergo critical review by several members of the research council. Prior to presentation at national meetings, practice run through sessions ensure optimal dissemination of information from our study group. The product of our research projects is publication in a peer-reviewed journal. All manuscripts are reviewed prior to journal submission. Producing quality research is a major priority of the Pediatric Spine Foundation. With the help of the Research Council, 2022 has been yet another productive research cycle and we expect to continue to make progress in 2023.

Research Council Process



The International Congress for Early Onset Scoliosis | ROME, ITALY

Dr. Burt Yaszay
ICEOS Chair



The 16th Annual International Congress for Early Onset Scoliosis and the Growing Spine (ICEOS) was held in Rome, Italy. Chaired by Dr. Burt Yaszay, the conference had over 146 participants from 26 countries. For some this was the first time getting to meet with international colleagues post-pandemic. Topics ranged from typical non-operative management to new innovative surgical techniques. Both faculty and the audience exchanged ideas and shared their success and their challenges in EOS. The pre-course chaired by Dr. Jack Flynn focused on the “The EOS Graduate”. To accommodate the record volume of submitted abstracts, the number of accepted paper presentations was increased from prior years. The Behrooz A. Akbarnia Award for Best Paper was given to PSSG member Dr. Jaysson Brooks. One of the highlights of the meeting was celebrating the Robert Campbell Jr. Award for Innovation which was given to Mr. David Marks. In addition to being faculty at the 1st ICEOS, Mr. Marks has been instrumental in the study and advancement of the growing rod. Other highlights included the keynote presentation by Dr. Behrooz Akbarnia and the Smith Family Lecture on local Italian winemaking. The meeting closed with “Words of Wisdom” from our most experienced faculty. It was truly an electric meeting with a motivated community of people inspired to do better for patients.





INTERNATIONAL TRAVEL GRANT

A key component to fulfilling our mission to help children with spine problems to live longer, better lives is the continual education of the physicians who will be treating them. The International Congress for Early Onset Scoliosis and the Growing Spine (ICEOS) is one of the greatest opportunities for individuals to assemble with other physicians from around the world to seek out solutions to the obstacles they might be facing as they treat EOS. In order to provide all individuals with the opportunity to attend this meeting, the Pediatric Spine Foundation provides a travel grant for up to \$2,500.

This grant is intended to fund travel expenses including air, hotel, meals, and meeting registration to an international conference addressing early onset scoliosis and/or thoracic insufficiency syndrome for surgeons from a resource challenged nation who may not otherwise have the opportunity to attend. For those who are interested in utilizing this grant they will need to submit an application that emphasizes their practice in pediatric spinal deformity, the financial challenges of international travel, and the challenges to accessing a local community of practitioners caring for EOS and/or thoracic insufficiency syndrome. We are excited to be able to provide this opportunity for the upcoming ICEOS conferences!

SAVE THE DATE!

17TH INTERNATIONAL CONGRESS ON

Early Onset Scoliosis and the Growing Spine

November
8-10, 2023

PROGRAM DIRECTOR



A. Noelle
Larson, MD

LOCAL HOST



Robert F.
Murphy, MD

PEDIATRIC SPINE REGISTRY RESEARCH HIGHLIGHTS



“I Don’t See Color”: A Multi-Center Evaluation of Race and Socioeconomic Status on UPRORs in Neuromuscular EOS

Principal Investigator: Dr. Jaysson Brooks

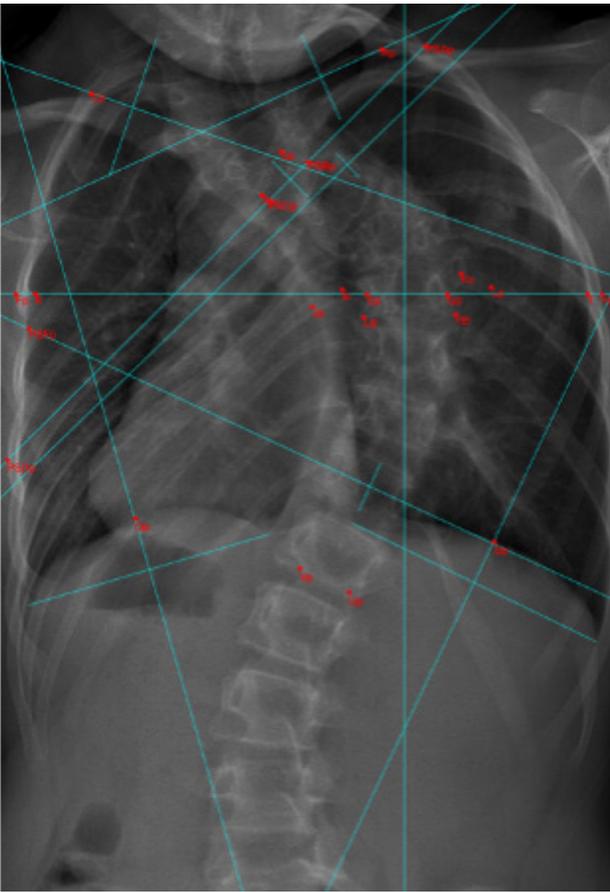
There is a very high complication rate in neuromuscular EOS (nmEOS) patients requiring growth friendly instrumentation (GFI). Studies have shown that a patient’s socioeconomic status (SES) affects their healthcare outcomes. The purpose of this study was to determine if there is a difference in SES between neuromuscular EOS patients who experience complications/UPRORs and those that do not. 67 patients with nmEOS, who underwent GFI were identified in the Pediatric Spine Registry. SES was measured using the area deprivation index (ADI), which is validated to the U.S. Census Block Group and includes domains of income, education, employment, and housing quality. Using a patient’s home address, the ADI website produces a national score between 1-100 with 1 meaning the least disadvantaged and 100 meaning the most disadvantaged. There was no significant difference in ADI between patients who experienced UPRORs (45.2) and patients who did not (36.5) ($p=0.17$).

When UPRORs were compared by race, white patients experienced significantly less mean UPROR events at 0.8 compared to non-white patients at 1.9 ($p=0.045$). Patients from the U.S. with nmEOS coming from lower socioeconomic backgrounds do not experience more UPRORs; however non-white patients with nmEOS do experience significantly more UPRORs after GFI. Race and SES are closely linked. In this first multicenter evaluation of SES in patients with nmEOS, this study found that patients experience different complications based on their race. We must strive to ensure that children with nmEOS receive equitable care and experience equitable outcomes.



Predicting Pulmonary Function from Thoracic Deformity Parameters in Pre-Operative EOS Patients

Principal Investigators: Dr. Noelle Larson & Dr. Sriram Balasubramanian



Thoracospinal deformities in early onset scoliosis often lead to thoracic insufficiency syndrome where lung growth and function are impaired. Pulmonary function tests are used to assess lung function but are challenging to obtain in young EOS patients. The objective of this study was to estimate PFT measures directly from radiographic deformity parameters as this would provide longitudinal outcomes data following surgery to help in clinical decision making.

Pre-operative radiographs and corresponding PFT (%FVC and %FEV1) measurements from 41 EOS subjects were obtained from the Pediatric Spine Registry. A total of 19 radiographic thoracic deformity parameters were measured using a custom software program. Multiple linear regression (MLR) models were developed to predict thoracic deformity measures. The MLR models predicted %FVC and %FEV1 with high precision. These models provide clinically useful, precise predictions of %FVC and %FEV1 based on key radiographic thoracic deformity parameters. Sensitivity analyses using such models can help guide surgical planning for deformity correction.





Major Cobb did not Decrease in 92% of Patients after VBT Surgery Following First Erect Radiograph

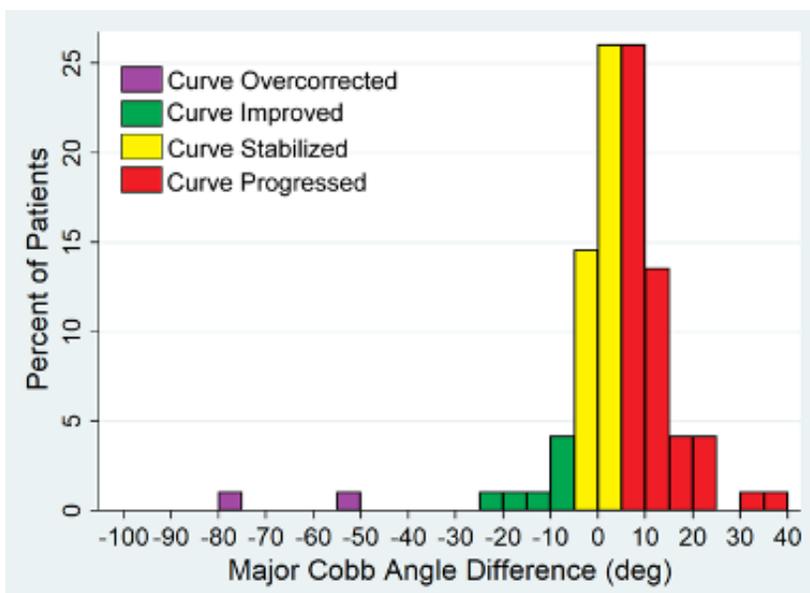
Principal Investigators: Dr. Lindsay Andras

In recent years, Vertebral Body Tethering (VBT) has become a growth modulating alternative to fusion treatment. However, the literature reports little difference between Cobb angles on the first standing post-operative x-ray and final follow-up, suggesting VBT is not modulating spine growth in a way that significantly affects Cobb Angle.

AIS patients who underwent VBT were identified using the Pediatric Spine Registry. 113 patients met inclusion criteria with mean age of 12.9 years and a mean follow up of 3.7 years. A mean of 6.6 levels were tethered. Preoperative mean Cobb angle was 51.1°, which corrected to a mean of 27.4° on first erect radiographs. At final follow up, mean major Cobb was 31.1°. 50.4% (57/113) of curves were stable (Cobb angles within 5° of their first erect radiograph on final follow up).



A total of 41.6% (n=47) had > 5° of increase in Cobb angle following the initial erect radiograph. Although this technique holds promise and many of the curves remained stable from first erect to final follow up (50%), less than 10% of VBT patients in this series demonstrated improvement in Cobb angle following first erect imaging, and over 40% had increasing Cobb angles over time. This highlights the importance of continued research and a need for caution prior to widespread adoption of this technique.





Risk Factors for Fusion Failure in Children Undergoing Occiput to C2 Rigid Instrumentation and Fusion

Principal Investigator: Dr. Richard Anderson

Modern studies investigating outcomes after pediatric occipital-cervical fusions have been limited to small or single center evaluations. Currently, there is significant clinical variation among pediatric spine surgeons regarding instrumentation, selection of bone graft material, use of bone graft extenders, post-operative immobilization, and other factors, with reported failure rates as high as 20%. The purpose of this study was to identify risk factors for fusion failure in pediatric patients undergoing occipital to C2 rigid instrumentation and fusion.

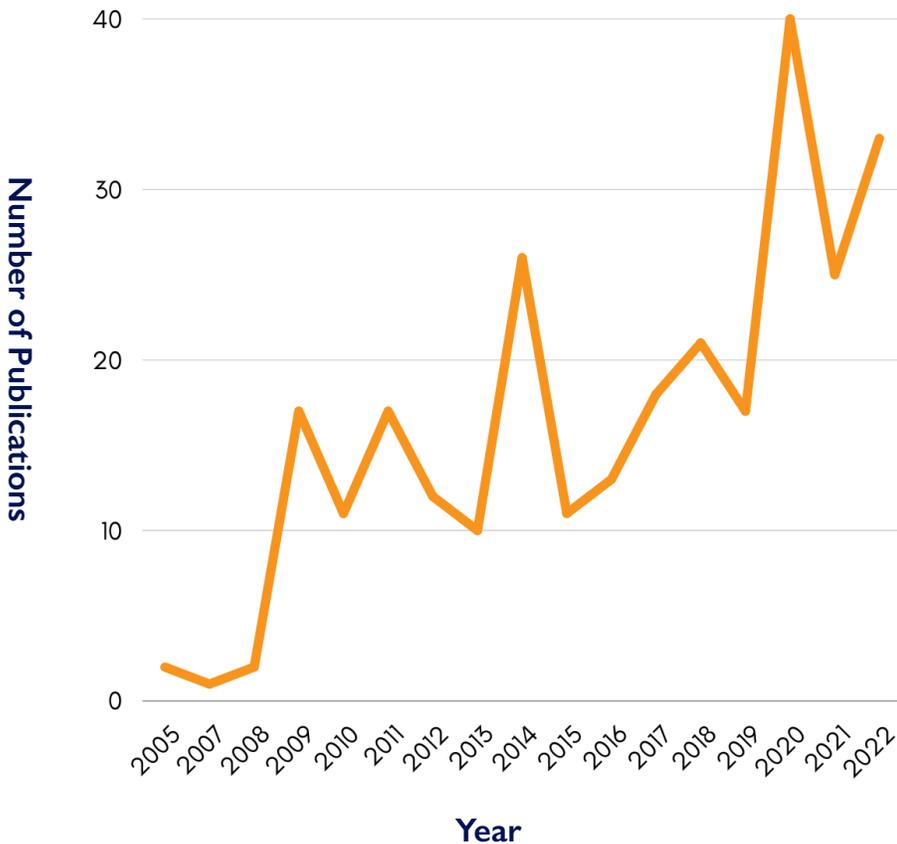


The Pediatric Spine Registry was queried and 53 patients were included in the study. Fusion failure was identified in 20/53 (38%) patients, a higher rate than commonly reported in the literature. Univariate analysis demonstrated that the use of structural rib autograft, a cable to secure structural bone graft, use of BMP, and postoperative immobilization with a hard collar were all associated with lower rates of fusion failure. Age, etiology (including Down syndrome), instrumentation type, unilateral instrumentation, and other variables did not appear to influence the risk for fusion failure. Multivariate regression analysis is currently underway and further investigation and additional patients are needed to confirm these findings.



ACADEMIC PRODUCTIVITY

In 2022 our team completed our first Patient Data Utilization report, delving into the granular levels of our patient data with the hopes of providing answers to big picture questions. This included a better understanding of etiology, treatment types, number of patients enrolled, and which sites were contributing the most sought after patients across research projects.



11,020

total patients
enrolled by the
end of 2022

4,868

total patients
contributed to
projects

51

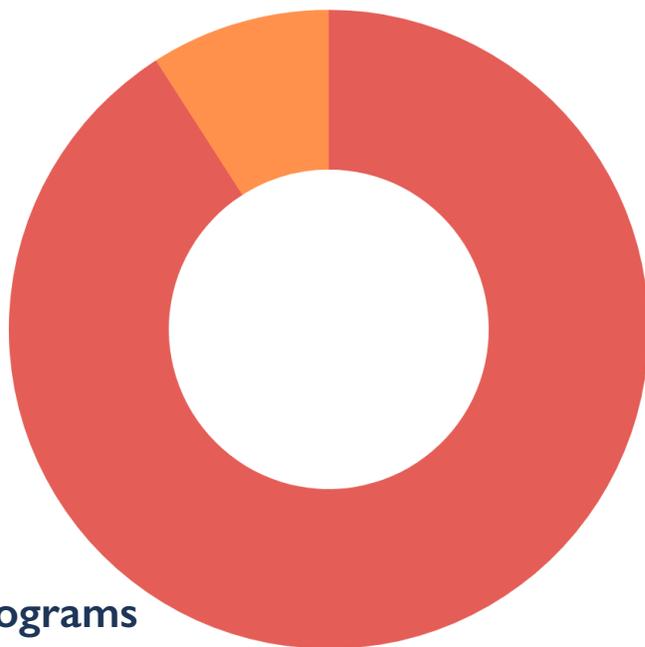
total projects
participated in

67

sites actively
involved in
projects

2022 FINANCIALS

Fundraising & Administration
9%



Programs
90%

Nonprofit expenses are split into three distinct categories: programs, administrative, and fundraising. The commonly accepted rule for nonprofits is that the combination of administrative and fundraising expenses remain at 25% or less. As a Foundation, we work hard to minimize administrative and fundraising costs so that we may direct as much funding as possible towards our mission. As a result, 90% of our funding can be directed to program expenses: research and publications, education, database infrastructure, research grants and family support. We are grateful to our donors and members whose consistent support allows us to maintain a minimal bottomline in terms of administration and fundraising.

Research and
Publication
Support

59%

Education

29%

Research Grants

8%

Database Infrastructure

5%

PUBLICATIONS & PRESENTATIONS

2022 Publications

Bowker R, Morash K, Mishreky A, Yaszay B, Andras L, Sturm P, Sponseller PD, Thompson GH, Pediatric Spine Study Group, El-Hawary R. 2022. Scoliosis Flexibility Correlates with Post-Operative Outcomes Following Growth Friendly Surgery. *Spine Deformity*.

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Glitzbecker MP, Du J, Dumaine AM, Ramo BA, Birch CM, Kelly DM, Sturm PF, Pediatric Spine Study Group. When Will You Succeed Casting Patients With Early Onset Scoliosis? Prospective Evaluation of Predictive Radiographic Parameters. 2022. *Journal of Pediatric Orthopedics*.

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Guzek RH, Murphy R, Hardesty CK, Means JB, Garg S, Smith JT, Roye BD, Glitzbecker MP, Sturm PF, Snyder BD, Poon SC, Poekochert C, Pediatric Spine Study Group, Anari JB. 2022. Mortality in Early Onset Scoliosis during the Growth-Friendly Surgery Era. *Journal of Pediatric Orthopaedics*.

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Marrache M, Suresh KV, White KK, Larson AN, Sponseller PD, Pediatric Spine Study Group. 2022. Connective Tissue Disease Patients Maintain Greater Distraction During Growth Friendly Surgery. *Journal of Pediatric Orthopedics*.

Matsumoto H, Ball J, Roye BD, Garg S, Erickson M, Samdani A, Skaggs D, Roye DP, Vitale MG, Pediatric Spine Study Group. 2022. Uncorrected Pelvic Obliquity is Associated with Worse Health-Related Quality of Life (HRQoL) in Children and their Caregivers at the End of Surgical Treatment for Early Onset Scoliosis. *Journal of Pediatric Orthopaedics*.

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Thank You!



We thank all those who continue to believe in our mission as much as we do. Our growth is able to come in large part because of you! A special thanks to:

Mr. Hansjörg Wyss

Friends and family, including Alisha Abhayakumar, Anya Abhayakumar, and Sahil Dadoo (pictured above) for their fundraising efforts. Through their event this year they were able to raise \$30,250!

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