

A year to

**LEARN
SHARE
GROW**

2016

ANNUAL REPORT



**CHILDREN'S
SPINE
FOUNDATION®**

President's Message

When people with a shared vision connect, anything is possible. Over the past year, I was impressed by the dedication of our clinicians, parents, and research team as we worked together to help children with spine problems live longer, better lives. Together, we asked questions and found answers; we shared knowledge and life stories. We truly embodied the 'learn, share, grow' philosophy and it drove our successes.

We connected internationally with other clinicians to improve treatment abroad. Dr. Claudio Fernandez from Argentina was the recipient of our first John Flynn Fellowship Award. He spent time with Dr. John Smith in Salt Lake City, Utah. Building on his experience, we will host 2 more fellows in 2017 and lead an international educational forum in Barcelona in May.

Our patient registry, which houses early onset scoliosis clinical data, grew to over 3400 patients. The information collected was used to evaluate treatments, reduce complications, and advise clinicians on best practices.

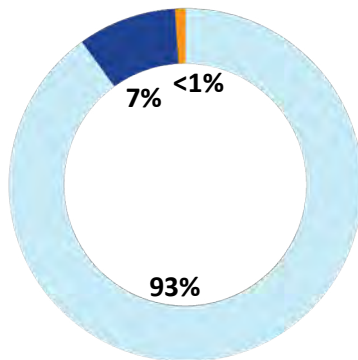
The hardship on families and children requiring repetitive care is enormous. In 2016 we continued to grow our Families In-Need program. We are proud to help multiple families obtain access to quality medical care.

This was all possible because of your tremendous support. Thank you for impacting the lives of thousands of children with complex spine disorders.

Jack Flynn, MD
President

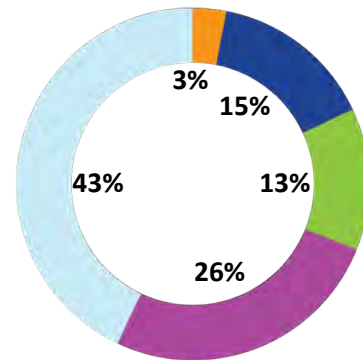
2016 FINANCIALS

EXPENSES



- Programs - \$458,327
- General & Administration - \$35,179
- Fundraising - \$250

PROGRAMS



- Family Programs
- Research Grants
- Education & Research Meetings
- Database Infrastructure
- Research & Publication Support

LOOK BACK ON 2016

Share in our success



LEARN

— about — *Early Onset Scoliosis*

Early onset scoliosis (EOS) is defined as abnormal spinal curvature (from side-to-side) diagnosed before the age of 10. Treatments for EOS aim to control the progression of curvature while allowing the spine and chest to grow. The Children's Spine Foundation registry accepts all children with EOS, regardless of treatment.

SHARE

— a — *Story*

The Families In-Need Program helps families with financial challenges access medical care. Through this program we've met wonderful families and children who have shared their story with us. Since the Program's initiation, we've helped 13 families obtain access to medical care in the United States. Family Grant applications are available on our [website](#).



GROW

— for the — *Future*

In 2016, the Children's Spine Foundation spent \$444,000 to support research in the area of early onset scoliosis. We published 10 articles, and presented from the podium 18 times. We focused on improving quality of life, determining the best treatments for our youngest patients, and reducing infection and complications for our surgical patients.



LEADING *the way...*



Josh Pahys, MD from Shriners Hospital for Children in Philadelphia was awarded the SRS Traveling Fellowship.

Sumeet Garg, MD from Children's Hospital of Colorado received the SRS New-Investigator Grant as well as the POSNA Start Up Research Grant. He was also promoted to Associate Professor.



Bob Campbell, MD from Children's Hospital of Philadelphia was awarded the prestigious CHOP Frontier award. This award recognizes programs that revolutionize care and fast forward advancements.

Norman Ramirez, MD from Hospital De La Concepcion in Puerto Rico was designated Chief Editor of the prestigious Puerto Rican medical Journal, Revista Salud Publica y Medicina.



Steve Huang, MD from Shriners Hospital for Children in Philadelphia was awarded the SRS Edgar Dawson Traveling Fellowship.

Jacob Schulz, Jaime Gomez, and Regina Hanstein from Children's Hospital at Montefiore in Bronx, NY won the Best Paper Award at the 2016 AAP National Conference & Exhibition Annual Meeting.



With over 30 sites in 5 countries, the Children's Spine Study Group is dedicated to finding the best treatments for patients with EOS.

...Around the **WORLD**

2016 PUBLICATIONS

Variability of surgical site infection with VEPTR at 8 centers: A retrospective cohort analysis Spine Deformity.

Garg S et al. Spine Deformity. 2016 Jan.

Factors Associated with Spinal Fusion after Posterior Fossa Decompression in Pediatric Patients with Chiari I Malformation and Scoliosis.

Hwang S et al. J Neurosurg Pediatr. 2016 Sept.

The Final 24-Item Early Onset Scoliosis Questionnaire (EOSQ-24): Validity, Reliability and Responsiveness.

Matsumoto H et al. Journal of Pediatric Orthopaedics. 2016 Jun.

Thoracic Insufficiency Syndrome.

Mayer O et al. Curr Probl Pediatr Adolesc Health Care. 2016 Mar.

Complications and Radiographic Outcomes of Posterior Spinal Fusion and Observation in Patients Who Have Undergone Distraction-Based Treatment for Early Onset Scoliosis.

Sawyer JR et al. Spine Deformity. 2016 Nov.

Sagittal Spine Length Measurement: A Novel Technique to Assess Growth of the Spine

Spurway AJ et al. Spine Deformity. 2016 Sept.

Reliability analysis of Cobb angle measurements of congenital scoliosis using X-ray and 3D-CT images.

Tauchi R et al. Eur J Orthop Surg Traumatol. 2016 Jan.

VEPTR Implantation After Age 3 is Associated With Similar Radiographic Outcomes With Fewer Complications.

Upasani VV et al. J Pediatr Orthop. 2016 Apr/May.

Surgeon Survey Shows No Adverse Events with MRI in Patients with Magnetically Controlled Growing Rods (MCGR).

Woon R et al. Spine Deformity. 2016 Nov.

2016 PRESENTATIONS

Quality of Life and Burden of Care in Patients with EOS Undergoing Casting.

Auran E et al. Presented as an oral presentation at ICEOS.

Growth Friendly Surgery is Effective at Treating Scoliosis Associated with Goldenhar Syndrome.

Connell B et al. Presented as an E-Poster at ICEOS.

Complications and Radiographic Outcomes of Posterior Spinal Fusion (PSF) and Observation (OB) in Patients Who Have Undergone Distraction-Based Treatment for Early Onset Scoliosis (EOS).

de Mendonca R et al. Presented as an oral presentation at POSNA.

Complications and Radiographic Outcomes of Posterior Spinal Fusion (PSF) in Patients with Spinal Muscular Atrophy (SMA) Following Growth Friendly Treatment.

de Mendonca R et al. Presented as an E-Poster at POSNA and an oral presentation at SRS.

Distraction-Based Surgeries Increase Thoracic Spine Length After 10 Lengthenings for Patients with Idiopathic Early Onset Scoliosis.

El-Hawary R et al. Presented as an oral presentation at SRS.

Superior Extension of Upper Instrumented Level in Distraction Based Surgery: A Surrogate for Clinically Significant PJK.

El-Hawary R et al. Presented as a Poster at AAOS.

Upper Foundations Implanted Cephalad to Upper End Vertebrae of Kyphosis Decreases Post-Operative Proximal Junctional Angle.

El-Hawary R et al. Presented as an oral presentation at SRS.

VEPTR Implantation to Treat Children with Early Onset Scoliosis without Rib Abnormalities: A Prospective Multicenter Study.

El-Hawary R et al. Presented as an oral presentation at POSNA and IMAST.

Spinal Muscular Atrophy; Growing Spinal Instrumentation Preserves Lung Volume and Maintains Quality of Life.

Feinberg N et al. Presented as an E-Poster at SRS.

A Prospective Study of Curve Correction and Thoracic Growth in Patients with SMA Following Rib-Based Growth Friendly Treatment.

Garg S et al. Presented as an E-Poster at ICEOS.

2016 PRESENTATIONS

(cont'd)

Hemoglobin Levels Pre- and Post-Treatment as a Surrogate for Disease Severity in Early Onset Scoliosis.

Glantzbecker M et al. Presented as an oral presentation at ICEOS.

Best Practice Guidelines For the Surgical Treatment of Early Onset Scoliosis.

Glantzbecker M et al. Presented as an E-Poster at SRS.

Does Initial Cast Correction Predict Treatment Success for Infantile Scoliosis?

Gomez JA et al. Presented as a Poster at POSNA.

Proximal Rib-Based Constructs in EOS: Long-Term Follow up and Survivorship.

Kondratyeva A et al. Presented as an E-Poster at ICEOS.

Spinopelvic Parameters Predict Development of Proximal Junctional Kyphosis in Early Onset Scoliosis.

Kubat O et al. Presented as an oral presentation at SRS and ICEOS.

Using Growth Friendly Constructs in Early Onset Scoliosis Secondary to Escobar Syndrome.

Margalit A et al. Presented as an E-Poster at ICEOS.

Complication Severity Score for Growth-Friendly Surgery Has Very Strong Inter and Intra Observer Agreement.

Michael N et al. Presented as an E-Poster at ICEOS.

Improvement of Pulmonary Function measured by patient reported outcomes in Patients with Spinal Muscular Atrophy after VEPTR surgery.

Mueller J et al. Presented as an oral presentation at ICEOS.

The Impact of VEPTR Treatment on Respiratory Assistance Requirement.

Nossov S et al. Presented as an oral presentation at IMAST and an E-Poster at SRS.

Results of Growth Friendly Surgery Versus Casting for the Treatment of EOS in Patients with Prader-Willi Syndrome.

Oore J et al. Presented as an E-Poster at ICEOS.

Preoperative Halo Gravity Traction in Severe Pediatric Spinal Deformity: A Single Center Prospective Study.

Pahys J et al. Presented as an oral presentation at SRS.

Comparison of Newly Implanted vs Converted Magnetically Controlled Growing Rods (MCGR) from the Post-United States Release.

Sawyer JR et al. Presented as an oral presentation at ICEOS.

Pelvic obliquity correction with pelvic screws is better than "S" hooks in distraction based growing spine constructs.

Schur M et al. Presented as an E-Poster at ICEOS.

Growing Rod and Vertical Expandable Prosthetic Titanium Rib Perform Differently for Idiopathic Early Onset Scoliosis at 5-year follow-up.

Sponseller P et al. Presented as an oral presentation at AAOS, a paper at POSNA, and an E-Poster at SRS.

How often do you Lengthen?: A Physician Survey on Lengthening Practice for VEPTR.

Striano B et al. Presented as an E-Poster at ICEOS.

Choice of Anchors – Rib vs. Spine: Importance of Proximal Anchor Number.

Vitale M et al. Presented as an E-Poster at POSNA and as an oral presentation at IMAST.

Classification of Early Onset Scoliosis Predicts Complications after Initiation of Growth Friendly Spine Surgery.

Vitale M et al. Presented as an oral presentation at AAOS, POSNA, and SRS.

Development of a Risk Severity Score Predicting Surgical Site Infection in Early Onset Scoliosis.

Vitale M et al. Presented as an oral presentation at ICEOS.

Multicenter evaluation of spinal deformity in skeletal dysplasias with growing rod systems.

White K et al. Presented as an E-Poster at SRS.

Surgeon Survey Shows No Adverse Events After MRI In Patients With Magnetically Controlled Growing Rods (MGCR).

Woon R et al. Presented as an oral presentation at ICEOS.

THANK YOU FOR YOUR *Support*

Did you know that the average six year old child with complex scoliosis will have more than twenty surgeries before they are 16? As parents, caregivers, and as a Foundation, this shared journey is one of growth and education. The Children's Spine Foundation commits to share our research and experiences to improve the quality of life for families on this treatment path.

Supporting this commitment is only possible with your help. Your donation helps fund 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.

SPECIAL *Recognition*

Mr. Hansjörg Wyss
DePuy Synthes Spine
Nuvasive
Zimmer Biomet

---Leadership---

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Sarah Mumford
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Lan Torii
Radiographic Measurer

Tricia Lane
Radiographic Measurer