ANNUAL REPORT
2020

At the Pediatric Spine Foundation Our Heroes are Standing TALL
While 2020 had its share of challenges, uncertainty, and change, there were many moments of simple greatness to be celebrated. In these moments, the heroic spirit of our patients, our staff, and our clinicians shone through.

Following last year’s merger of two study groups, our researchers were well positioned to answer the hardest questions about the growing spine. While our in-person collaboration was limited, Research Interest Groups continued to Zoom regularly, developing a record number of research projects to pursue. In the educational arena, the annual International Congress of Early Onset Education (ICEOS) was held virtually, with many of our Pediatric Spine members receiving honors and awards!

Lastly, we are also excited to announce our new name - the Pediatric Spine Foundation. While the name is a small change, it reflects a momentous milestone for us. With over 153 participating clinicians at 72 sites around the world, our registry has grown to almost 9,000 patients. We are proud to be the largest spine deformity research organization in the world and the largest organization dedicated to better outcomes for patients with spine deformity.

Sincerely,

Ron El-Hawary, MD
HERO:

An ordinary individual who finds strength to persevere and endure in spite of overwhelming obstacles.

- Christopher Reeve
FINANCIALS

Programs

74%
Research and Publication Support

13%
Education and Research Meetings

9%
Database Infrastructure

4%
Research Grants

Expenses

Programs: $888,190

Fundraising: $1,055

Administration: $47,060
Research Interest Groups (RIGs) are small teams of interested clinicians with similar research interests. RIGs aim to be collaborative, innovative, and inclusive. In 2020, there were 12 active groups with over 80 participating investigators, resulting in 60 new research projects. These groups aim to cover a wide variety of topics, some of which include surgical techniques, non-operative care, complications, graduates, neuromuscular scoliosis, and growth modulation.

In November 2020, the International Congress of Early Onset Scoliosis, was virtually attended by 131 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.
The etiology of idiopathic EOS (iEOS) is a mystery. It is unknown why scoliosis occurs in these children when the risk in families is low and the kids are otherwise healthy. The goal of this study is to discover the genetic basis of iEOS. With our enrollment goal of 100 PSSG patients, we hope to form the foundation of future multi-center investigations to better understand the origins of iEOS and its disease mechanisms.

Determinations of Best MCGIR Implementation Strategy using Distraction Intervals
Drs. Kenneth Cheung & Michael Vitale

This study is a hospital-based, cluster stratified randomized control trial. With 22 participating sites and 20 patients currently enrolled, we are looking at the effect of a 6-week lengthening interval compared to a 16-week lengthening interval for EOS patients between 5 & 9 years old. These patients must have a major coronal curve measuring over 50 degrees and will be followed for three years.

Long Term Quality of Life
Dr. Jeff Sawyer

We are obtaining quality of life data from early onset scoliosis patients that have now completed treatment and are moving into adulthood. It is hypothesized that adult EOS patients who have undergone surgical intervention have differences from age-matched peers in social function and quality of life. There are currently 80 enrolled participants in this study from 9 different institutions.

Bracing versus Casting in the Treatment of Idiopathic Early Onset Scoliosis
Drs. Stuart Weinstein & Lori Dolan

With 440 patients to be enrolled and 41 participating sites, we hope to evaluate the immediate outcomes of casting and bracing in IEOS. We will do this by using a multi-center, partially randomized, patient preference design by comparing the risk of curve resolution in subjects treated with serial casting to those treated with bracing.

Genetics of Idiopathic EOS
Dr. Carol Wise

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Through our Families-In-Need program, many patients across the United States can apply and be granted assistance for access to medical care. This program helps to remove some of the challenges that families face as they seek out treatment, allowing them to find hope and answers through their scoliosis journey.

In addition to managing 4 prospective studies, PSSG launched the surgeon-specific quality dashboard. This allows registry participants to compare their performance for common items such as OR time and infection rate to others in the registry. Ultimately, this will result in improved patient outcomes.

The education of our peers and our patients is of utmost importance. In addition to the annual ICEOS meeting, we have updated our website to include patient and physician education. Here, the latest Study Group research is summarized, allowing interested individuals to easily access our knowledge and experience in the form of quality research.
Publications


Swarup I, MacAlpine EM, Mayer OH, Lark RK, Smith JT, Vitale MG, Flynn JM, Anari JB; Pediatric Spine Study Group, Cahill PJ. Impact of growth friendly interventions on spine and pulmonary outcomes of patients with spinal muscular atrophy. Eur Spine J. 2020 Aug 18.


Presentations


The Pediatric Spine Foundation would like to thank you for all of your heroic efforts throughout this year. Because of you we have been able to fulfill our mission of helping children with spine problems to live longer, more fulfilling lives.