

Pediatric Spine Foundation

2021 Annual Report



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President's Message



2021 was a year made up of small steps forward and daily gratitude for each of those steps. Life within the Pediatric Spine Foundation was no different. We were grateful to welcome many new members and a few new institutions. We were thankful to again see many patients in person and to meet with colleagues around the same table. We were appreciative of our many donors and supporters, without which we wouldn't be able to do what we do.

Throughout the year our Research Interest Groups continued to Zoom and meet regularly, developing research projects and producing 30 publications. One research initiative I am most proud of is starting a spondylolisthesis and back pain working group to help address a very prevalent and important issue, which until now has been understudied by the pediatric spine community. In the education arena, the annual International Congress of Early Onset Scoliosis (ICEOS) was held in-person in Salt Lake City with our very own Dr. John Smith as local host and chaired by Dr. Jack Flynn. Many of our Pediatric Spine members received honors and awards, including Dr. Behrooz Akbarnia.

As is often the case, it is rewarding to look back, but what really deserves our focus is the present. With over 180 participating clinicians at 80 sites around the world, our registry has over 10,400 patients. We have 60 active projects with many new members leading us closer to our mission. 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.

With many thanks,

A handwritten signature in black ink that reads "David L. Skaggs". The signature is written in a cursive, flowing style.

Dr. David Skaggs



Hospital-Based Cluster Stratified Randomization Control Trial:

Determination of Best Magnetically Controlled Growing Rods
Implementation Strategy using Distraction Intervals

Principal Investigators:

Kenneth Cheung, MD & Michael Vitale, MD, MPH

Kenneth Cheung, MD, is the Jessie Ho professor in Spine Surgery and Chair Professor at the University of Hong Kong and the Editor-in-Chief for the Journal of Orthopaedic Surgery.

Dr. Cheung is a global leader in the treatment of spinal deformities and a past President of the Scoliosis Research Society. His team has published extensively on a new method of assessment of flexibility of the spine using the "fulcrum bending" technique.

His research interests are in the genetics of intervertebral disc degeneration and scoliosis, stem cell regeneration of the disc, and the development of novel surgical technologies for the treatment of spinal deformities.



Michael Vitale, MD MPH is the Ana Lucia Professor of Orthopedic and Neurosurgery and Vice Chief, (Quality and Strategy) of the Department of Orthopaedics at Columbia University Medical Center. He is also Chief of Pediatric Orthopaedics for the New York Presbyterian health system, where he has developed his clinical focus in the care of children with spinal deformity since joining the staff in 2001.

Dr. Vitale has served as Chairman of the International Pediatric Orthopaedic Symposium and President of the Children's Spine Foundation. He founded the Project for Safety in Spine Surgery, which hosts the annual Summit for Safety in Spine Surgery. In addition to his clinical practice, Dr. Vitale has made a lifelong commitment to clinical research with almost 200 peer reviewed publications largely focused around pediatric spine surgery.

The magnetically controlled growth rod (MCGR) system is a remotely distractible, magnetically controlled growing rod. The remote capabilities allow for less invasive and less time-consuming outpatient distraction visits, which solves many of the problems facing current growing rod technologies.

The purpose of this study is to determine the effect of a 6-week lengthening interval compared to a 16-week lengthening interval on spinal growth in EOS patients between 5 and 9 years of age with a major coronal curve over 50 degrees undergoing MCGR treatment within 3 years. 20 sites, 17 domestic and 3 international, are open for enrollment with 35 patients currently enrolled. This includes 22 patients in the 16 week group and 13 patients in the 6 week group. The target enrollment for this study is 210.



A Prospective Analysis of Long-Term Clinical Outcomes and 3-D Spine Growth in Anterior Vertebral Body Tethering

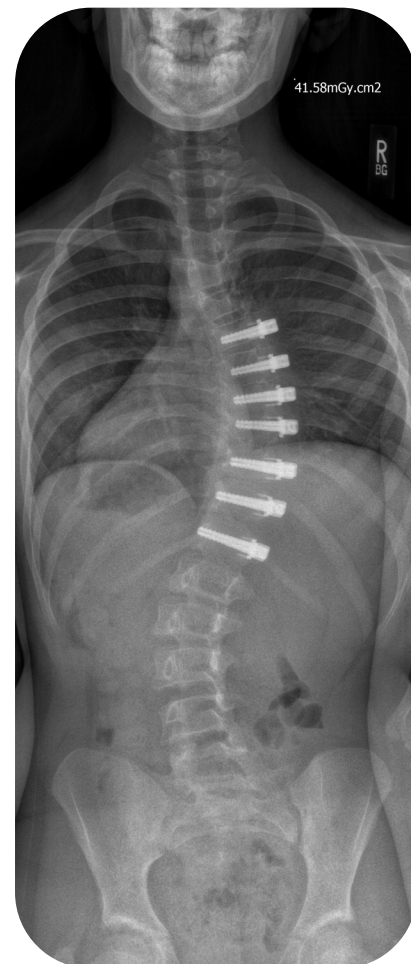
Principal Investigator: Ron El-Hawary, MD

Anterior vertebral body tethering (AVBT) is a novel growth modulation technique that was approved by the FDA under a Humanitarian Device Exemption (HDE) in August 2019. AVBT utilizes a non-fusion spinal device intended to treat idiopathic scoliosis, an abnormal curvature in the spine that occurs without a known cause, in young patients whose bones have not fully matured.

Bone screws are placed into the patient's spine on the side of the spinal curvature and a cord is then secured to the bone screws. During surgery, the surgeon will apply tension to the cord to partially straighten the patient's spine. After surgery, the cord continues to straighten the spine while the patient continues to grow.

The purpose of this study is to report the long-term clinical outcomes of 106 patients treated with AVBT. We will look at spine growth using 3D reconstructions created from patient x-rays, maintenance of a major Cobb angle less than or equal to 50 degrees at skeletal maturity, and complications associated with both the procedure and the device. Patients will be followed for 5 years after their surgery.

We will also collect collagen growth marker (CXM) samples from patients throughout the study to help determine how quickly their bones are growing at different points in time. We hope this information combined with clinical outcomes will help us decide the best time to perform the surgery for growing patients in the future.



Ron El-Hawary, MD, is Chief of Orthopaedics and Director of Scoliosis / Orthopaedic Trauma at the IWK Health Centre. He is Professor, Department of Surgery with cross-appointments with the School of Biomedical Engineering and with the Division of Neurosurgery at Dalhousie University in Halifax, Nova Scotia, Canada.

He is currently Past President of the Canadian Pediatric Orthopaedic Group, Past President of the Pediatric Spine Foundation, and Chair of the Pediatric Spine Study Group. Dr. El-Hawary is also serving as Chair of the Scoliosis Research Society's Education Resource Committee.

His clinical interests are varied, with the main focus being the correction of spinal deformity. This includes the treatment of all forms of scoliosis, including early onset scoliosis (casting, growing rods, VEPTR, MAGEC, TROLLEY, posterior dynamic deformity correction - Apifix, vertebral body stapling - VBS, vertebral body tethering - VBT, and thoracoscopic techniques).



Bracing vs. Casting in the Treatment of Idiopathic Scoliosis



Principal Investigators:
Stu Weinstein, MD & Lori Dolan, PhD

For the past 15 years, serial casting has been the most favored non-surgical treatment for idiopathic scoliosis. Although this treatment method is quite popular, casts are usually applied with the child using general anesthesia or sedation in the operating room. Although several retrospective, uncontrolled studies report favorable outcomes after casting there are few studies reporting the outcomes of bracing which does not use anesthesia for application, hence the need for this study.



With the goal of enrolling 220 patients, this study uses a multicenter, prospective hybrid research design, which will combine two methods of treatment assignment (randomized and parent preference) and an embedded internal pilot study for sample size re-estimation. Patients will be treated either with serial casts or a full-time brace and followed until curve resolution, failure or palliation (neither resolution nor failure after 2 years of treatment). Currently we have 41 sites enrolling patients with 30 patients enrolled. Results of this study will provide clinicians and families with the evidence to support informed treatment decisions.



Stuart Weinstein, MD, is the Ignacio V. Ponseti Chair and Professor of Orthopaedic Surgery and Professor of Pediatrics at The University of Iowa. Dr. Weinstein is an NIH funded researcher. He has published more than 220 scientific articles in peer review journals. His research work has focused on spinal deformity in children, children's hip and foot problems, and the natural history and long-term outcome of pediatric musculoskeletal conditions. Dr Weinstein is past president of the American Academy of Orthopaedic Surgeons, The American Orthopaedic Association, The American Board of Orthopaedic Surgery, The Pediatric Orthopaedic Society of North America, The United States National Action Network of the International Bone and Joint Decade, The International Center for Orthopaedic Education (ICOE), and Doctors for Medical Liability Reform (DMLR).

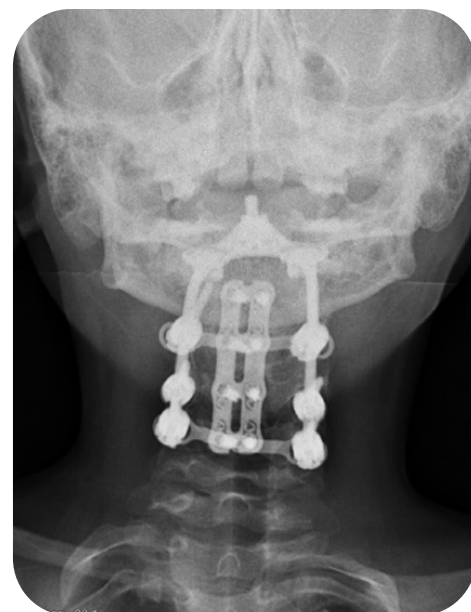


Dr. Lori Ann Dolan has been involved in pediatric orthopaedic research at the University of Iowa since 1990 and co-lead the Bracing in Adolescent Idiopathic Scoliosis project with Dr. Stuart Weinstein. She has a bachelors degree in Nursing, a masters in Educational Measurement and Statistics and a PhD in Health Management and Policy. She has published widely on the treatment and long-term outcomes of early- and adolescent-onset idiopathic scoliosis, and has presented this work at orthopaedic and orthotic conferences. She is a member of the Pediatric Society of North America, the Scoliosis Research Society and on the executive board of the International Society of Scoliosis Orthopaedic and Rehabilitation Treatment.

Cervical Spine Disorders

Research Interest Group Leader: Joshua Pahys, MD

Many of our patients are diagnosed with scoliosis, however a small percentage have cervical spine disorders. This may be in addition to scoliosis or standalone. These disorders can occur at birth or due to trauma. Most often they are seen in children that have Down Syndrome, Klippel-Feil syndrome, or other bone disorders. While rare, cervical spine injuries or abnormalities can cause spinal cord problems or abnormal brain development for the child and must, at minimum, be observed, and sometimes addressed with surgery. Surgery aims to prevent and/or correct deformity and instability, minimize pain, and prevent the loss of function.



The cervical spine registry is a part of the Pediatric Spine Registry. It is specifically focused on issues associated with Down Syndrome, occipital-cervical fusions, congenital anomalies, and traumatic injuries of the cervical spine. There are currently over 500 patients enrolled. Dr. Josh Pahys leads the cervical spine research interest group with 16 members of the Pediatric Spine Study Group actively participating. Current projects include cervical spine fusions, spine motion after occipital fusion, and the development of a new classification system for craniocervical anomalies.



Joshua M. Pahys, MD is an attending pediatric spine surgeon at Shriners Hospitals for Children – Philadelphia since 2010, where he also serves as the residency program director. He is an adjunct clinical associate professor of Orthopaedic Surgery at the Sidney Kimmel Medical College of Thomas Jefferson University. He is an active member of the American Academy of Orthopaedic Surgeons, Scoliosis Research Society, Harms Study Group, and Pediatric Spine Study Group, and Vice President of the Philadelphia Orthopaedic Society. Dr. Pahys obtained his medical degree from Jefferson Medical College in Philadelphia, completed his Orthopaedic Surgery residency training at Einstein Medical Center in Philadelphia, followed by a fellowship in adult and pediatric spine and spinal deformity at Washington University in St. Louis. Dr. Pahys is an author on over 100 peer reviewed journal publications, 14 book chapters, and has presented at multiple national and international conferences. He spends his free time hiking the national parks with his wife, three kids, and Stella their great dane.

Patient Support



A new diagnosis of early onset scoliosis can leave parents and children in a fog, unclear about what the future might look like. While definitions and treatment options are able to provide answers to many questions, there is a different source of comfort that comes from personal anecdotes. The Pediatric Spine Foundation aims to be a pillar of support by providing this through our patient stories that can be found on our website in addition to our other social media outlets which include Facebook and Instagram.

Recently, Dr. Jaysson Brooks, an active member of our study group and physician at Texas Scottish Rite for Children, hosted our first Instagram Live interview! Waylon and his mom shared firsthand what it was like to go through casting from the toddler and parent's perspective. We learned about the fears, the difficulties, and the triumphs of Waylon's treatments and how he is doing today.

Stay tuned for more upcoming interviews as we hear from a variety of physicians and their patients who are undergoing treatment for early onset scoliosis.



Instagram: @pediatricspine

ICEOS

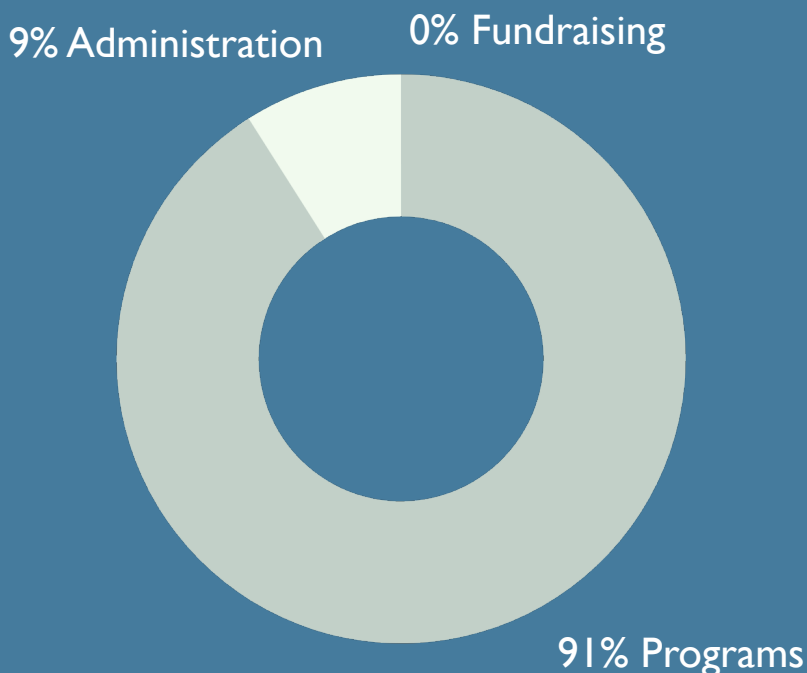


In November 2021 we were thrilled to hold the International Congress on Early Onset Scoliosis and the Growing Spine (ICEOS) in Salt Lake City, Utah, chaired by one of our very own members, Dr. Jack Flynn. Over 100 physicians from around the world were able to participate in workshops, presentations, and debates on the best treatment methods for children with scoliosis. The energy was palpable as we learned from one another and collaborated on how we might progress toward our unified goal of treating children with early onset scoliosis. We were also proud to have one of our members, Dr. Behrooz Akbarnia, be presented with the Campbell Award. This award is granted annually to one physician for their outstanding contribution to children with EOS. As Dr. Akbarnia graciously accepted this award it was clear that many lives have been touched by him and his dedication to this work.



2021 Financial Review

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 direct as much funding as possible towards our mission through program expenses. These programs include research and publication support, 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

64%



Education

22%



Database
Infrastructure

7%



Research
Grants

6%



Family
Support

1%

Publications

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Presentations

- Ellen Parker, Mohammed Al Anazi, Pediatric Spine Study Group, El-Hawary R. Low Radius of Curvature Growth Friendly Implants Increase the Risk of Developing Clinically Significant Proximal Junctional Kyphosis. Presented at the International Congress on Early Onset Scoliosis (ICEOS) Annual Meeting.
- Compton E, Gupta P, Gomez J, Illingworth K, Skaggs D, Sponseller P, Samdani A, Hwang S, Oetgen M, Schottler J, Thompson GH, Vitale M, Smith JT, Andras L, Pediatric Spine Study Group. How low can you go? Evaluation of Implant Density in Growing Construct Conversion to Posterior Spinal Fusion for Early Onset Scoliosis. Presented at the Pediatric Orthopaedic Society of North America (POSNA) Annual Meeting.

- Garg S, Kim E, Gupta P, Woon R, Pediatric Spine Study Group. Current Practices for Running Expansion Clinics for Patients with Magnetic Controlled Growth Rods (MCGR): Survey of Experts. Presented at the Pediatric Orthopaedic Society of North America (POSNA) Annual Meeting.
- Glitzbecker MP, Du J, Dumaine A, Kelly D, Sturm P, Ramo B, Pediatric Spine Study Group. Can traction films predict cast correction? Presented at the International Congress on Early Onset Scoliosis (ICEOS) Annual Meeting.
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