



Annual Report 2023

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A Message From Our President

Jack Flynn, MD



In 2023, we truly took the Pediatric Spine Foundation to the next level. With a very successful merger accomplished, we made strategic changes to strengthen our team effort to care for children with complex spine deformities. One of the key moves was to create a single moment each year where all those who are passionate about improving the lives of these children—clinicians, researchers, medical device innovators—can gather to advance the field. To make that moment the annual International Congress on Early Onset Scoliosis (ICEOS), we've moved the Research Factory from winter to fall, so it is now part of ICEOS week. We've also changed our leadership service calendar so that we pass the batons to our successors at ICEOS as well. In Charleston, I had the great honor to pass the baton on the PSF Presidency to the world-renowned pediatric spine surgeon and thought-leader, Dr. Paul Sponseller. Going forward, the PSF winter meeting will be a strategic planning meeting for leadership focused on improving our research and education efforts and assuring financial stewardship in a moment when high-quality multicenter research is ever more expensive.

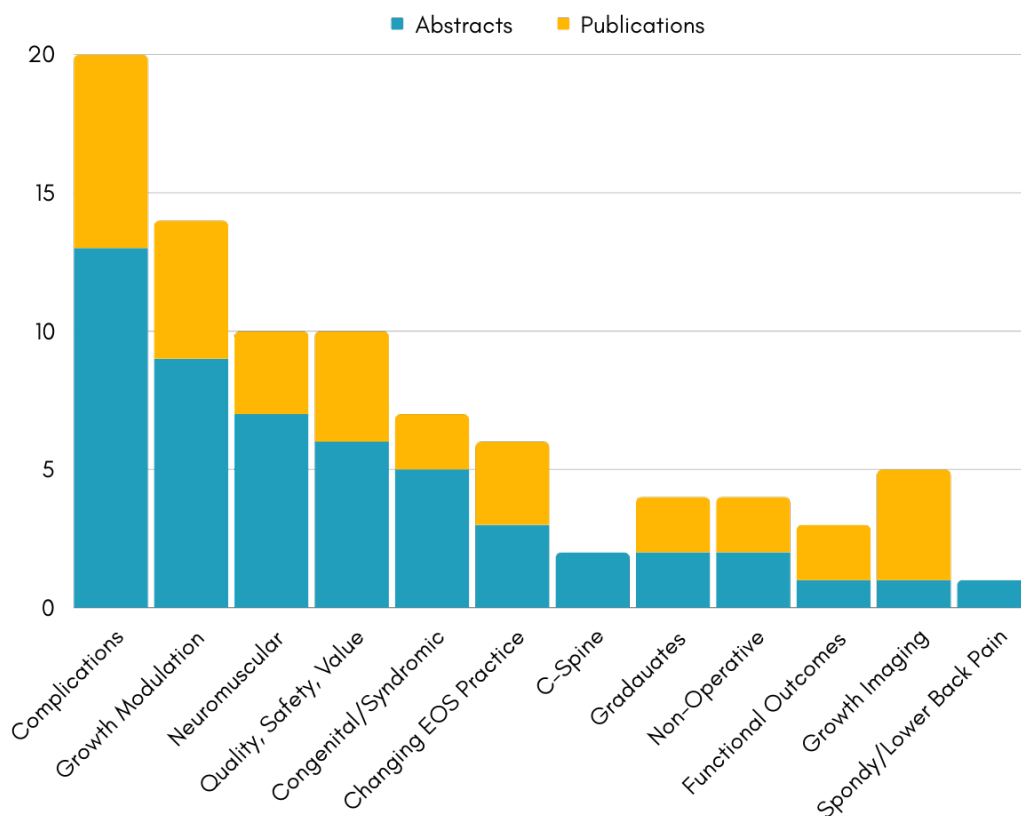
Surgeons from all over the world are saying that ICEOS 2023 in Charleston was the best ever! With 192 registrants from 21 countries, it was the biggest group we've ever assembled to share research and debate the best treatment of complex spinal problems in children. We had strong support from our industry partners, and a wonderful venue and city to enjoy. Many thanks to Noelle Larson for assembling a spectacular program! ICEOS is truly the must attend event for the pediatric spine surgeons of the world. We've also had an incredibly productive year of research. PSSG, under the

leadership of Amer Samdani and now Lindsay Andras, had a highly productive Research Factory in Charleston. We have 200 PSSG members from 82 institutions in 12 countries....and growing every year. We added 17 new Candidate Members—energized rising stars in the field with great ideas and lots of motivation to improve our care. We now have 12,469 unique patients with 130,600 evaluations and 201,800 images in our database—the largest spine database in the world. By October, we had 52 accepted abstracts and 34 publications in 2023, with many more in the works. It takes substantial resources for Tricia St. Hilaire, our Executive Director, 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, PSF 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!



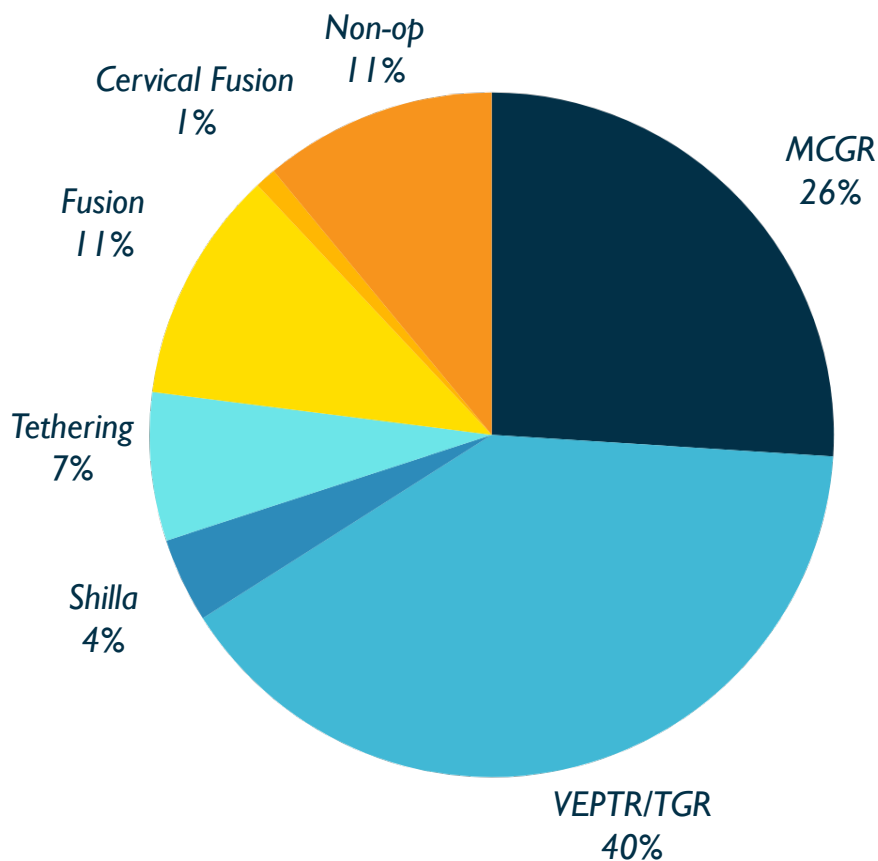
As the largest pediatric spine database in the world, we aim to produce high quality data that results in accepted abstracts, publications, and ultimately progress for our community and the future of our patients. This includes productivity by each Research Interest Group (RIG), analyzing how our patient data is utilized in retrospective studies and ongoing prospective studies.

RIG Productivity



Unique Patients Used in Studies by Primary Treatment

Data from 4,600 patients was used in the studies produced in 2023.



RESEARCH HIGHLIGHTS

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

Principal Investigator: Ron El-Hawary, MD

Approved under a Humanitarian Device Exemption (HDE) in August of 2019, the Anterior Vertebral Body Tethering system was a unique, less invasive, non-fusion spinal device intended to treat idiopathic scoliosis. To better understand the outcomes of this type of treatment, this study aims to analyze spine growth, maintenance of the Cobb angle, and complications associated with the procedure and/or device for five years after the patient has their initial surgery.

This study also collects 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. Currently, 58 patients are enrolled with a goal of 106 patients total.

Bracing vs. Casting in the Treatment of Idiopathic Early Onset Scoliosis

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

This multicenter, prospective study is currently being run through PSSG by Stuart Weinstein, MD and Lori Dolan, PhD from the University of Iowa. Patients under the age of 4 with early onset scoliosis are treated with either serial casts or a full-time brace and followed until curve resolution, failure or palliation. Curve resolution is defined by curve improvement to less than 15 degrees, while failure is defined by 20+ degrees of curve progression, resulting in a curve greater than 50 degrees. Currently, there are 66 patients enrolled with an enrollment goal of 220. Results of this study hope to provide clinicians and families with further evidence to support informed treatment decisions regarding bracing and casting.



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

Principal Investigators: Kenneth Cheung, MD & Michael Vitale, MD, MPH

The magnetically controlled growth rod (MCGR) system is a growth-friendly treatment that allows for less invasive, time-consuming outpatient visits through its ability to lengthen rods with an external magnetic device. This solves many of the surgical, time intensive difficulties that current growth-friendly implants face. This study hopes to increase our understanding of this treatment by determining 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.

Currently there are 19 sites, 17 domestic and 2 international, that are open for enrollment with 80 patients currently enrolled. This includes 61 patients in the 16 week group and 19 patients in the 6 week group. In a recent interim analysis, no difference was found in spine height or complications when comparing the 6 week and 16 week arm groups. We expect this trend to continue, but are excited to see the final results in the next few years.



Research Grants



Six Minute Walk Test in Children with EOS

PI: Amy McIntosh, MD

Grant Amount: \$10,000

Children with early onset scoliosis (EOS) have compromised pulmonary function, requiring them to undergo multiple treatments to correct their curves and to improve pulmonary function. Pulmonary function tests (PFTs) are the gold standard for assessing pulmonary function but require costly equipment, may not change after treatment, and are effort dependent. This study hopes to assess and determine reference values for the six-minute walk test (6MWT) and the 6-minute push test (6MPT). The 6MWT is an inexpensive self-paced, submaximal exercise test that assesses functional aerobic capacity and estimates physical fitness. The 6-minute push test (6MPT) is the non-ambulatory equivalent of the 6MWT in children who self-propel a wheelchair. The 6MWT provides age and gender-based reference values. Normative 6MWT and 6MPT scores do not exist in the EOS population and have vast potential by evaluating changes in aerobic function due to various surgical, respiratory, physical and/or occupational therapy, and other treatment interventions at short- or long-term follow-up. Collaborations with other centers including low-income countries who do not have PFTs will allow for developing developmental trajectories by EOS type and even possibly by region of the world. Measuring function also allows for precision practice by quantifying whether individual patients' function has changed.



Part-time Bracing in Juvenile Idiopathic Scoliosis - A Multicenter Prospective Study

PI: Benjamin Roye, MD

Grant Amount: \$20,000

Juvenile Idiopathic Scoliosis (JIS) presents unique clinical challenges. The optimal management approach for smaller curves in JIS remains uncertain, leaving physicians with a choice between brace treatment and observation. In order to shed light on this difficult question, we will be conducting a multicenter research initiative to investigate the comparative efficacy of part-time bracing versus observation in the management of JIS. Our primary goal is to ascertain which treatment approach yields better outcomes concerning spinal curve progression, patient compliance, and Health-Related Quality of Life (HRQoL) outcomes. Additionally, we seek to identify patient and brace characteristics that might be predictive of permanent correction of the spinal deformity.

The primary goal of this study is to develop a frailty score for patients with early onset scoliosis using available pre-operative risk factors and intra-operative variables through machine learning models that were previously developed in our pilot study. More specifically, we intend to use our experience in the development of previous risk severity scores as well as pilot work using the American College of Surgeon's NSQIP database to develop a frailty model which predicts excessive length of stay which may serve as a proxy for perioperative complications.



Developing a Frailty Model to Identify Pediatric Spinal Deformity Patients at-risk for Prolonged Hospital Stay

PI: Michael Vitale, MD, MPH

Grant Amount: \$20,000



ICEOS Travel Grant

Yehia El-Bromboly, Zagazig University, Egypt

As a worldwide organization, the Pediatric Spine Foundation aims to provide educational opportunities for all of its members. 2023 was the second year that we were excited to provide a travel grant to participate in the International Conference on Early Onset Scoliosis (ICEOS). This year, Dr. Yehia El-Bromboly from Zagazig University in Egypt was able to attend. He was connected to the Pediatric Spine Foundation through his fellowship at Dalhousie University in Halifax, Nova Scotia with Dr. Ron El-Hawary and started his own practice in 2020, completing about 60 surgeries each year. He states, "I was privileged to attend this year's ICEOS meeting. It was truly an enlightening experience as I was able to discuss advances and technical aspects of the evolving field of Early Onset Scoliosis with world-class surgeons and researchers. I hope that I will be able to implement some of what I learnt in my practice and pass it on to my fellow colleagues in my area."

The 17th Annual International Congress for Early Onset Scoliosis (ICEOS) was held in Charleston, South Carolina. Chaired by Dr. A. Noelle Larson, the conference had record attendance with 193 participants from 20 different countries around the world. Our local host was Dr. Robert Murphy. We had a record attendance and a high level of academic engagement with 39 research papers and multiple excellent technical presentations including masters techniques and debates on how to best treat patients with early onset scoliosis. The Behrooz A. Akbarnia Award for Best Paper was given to Dr. Renè Castelein for his work entitled, Surgical Treatment of Neuromuscular Early Onset Scoliosis with a Bilateral Posterior One-Way Rod Compared to the Spring Distraction System: A Randomized Controlled Trial. Our keynote speaker was Dr. Larry Lenke who reflected on revision of pediatric spine



deformity surgery in adolescents and adults. Finally, Dr. Paul Sponseller received the Robert Campbell Jr. Award for Innovation for his tireless dedication to the treatment of EOS and special focus on new technologies for the treatment of syndromic patients. The meeting also included new sessions with a focus on perioperative care and the neurosurgical practice as well as a new small group session requiring table groups to work through challenging clinical scenarios together. Our Smith Family Lecture informed us on local sustainable oyster farming and allowed us to taste some hand-raised oysters. In short, ICEOS 2023 was a pivotal learning experience as well as a time of case sharing and catching up with colleagues. We look forward to seeing you at ICEOS 2024 in Arizona.

Noelle Larson, MD
ICEOS Chair, 2023

ICEOS

Research can be grueling, taking years to complete and sometimes leaving both the researcher and our patients wondering how these efforts are directly affecting them. As we have collected stories from our community we have discovered a meaningful connection being made that is revealing positive treatment outcomes due to the influence of published research articles within our study group.

Is Travel Too Much of a Burden?

Dr. Robert Murphy and his patient, David Kee

Patients and families who undergo growth friendly (GF) treatment for early onset scoliosis are often required to travel long distances to the clinic and hospital multiple times each year. This requires caregivers taking days off work, patients missing school, and can be a significant burden for a variety of other reasons. Dr. Robert Murphy sought to quantify the time and travel burden of these patients to provide families with an expectation as they begin their GF treatment journey.



In this study a total of 300 patients from four high volume centers within the Pediatric Spine Study Group were included. Demographics, scoliosis etiology, GF implant, visit type, and driving distance were analyzed. There were a total of 5,899 encounters (average 18 encounters per patient; range 3 -75), broken down into 2,521 clinical office visits, 2,045 surgical lengthening encounters, 1157 MCGR lengthening encounters, 149 spinal fusions, and 27 fusion revisions. Eighteen days off work estimated a loss of \$3,643.50 in income.

Patients traveled a median distance of 157.8 miles between their home and treating institution per encounter (range 2.4 - 5,654), with a cumulative median driving distance of 2650.6 miles for the entirety of their treatment (range 28.6 - 90,552), at an estimated cost of \$1,656.63.

While these numbers bear their own weight, many patients have found

that the time and distance traveled are often exchanged for an increased quality of life. This was the case for David Kee, a scoliosis patient that was diagnosed at the age of 3 and underwent surgery to place MCGR rods at age 6. Initially, his parents were concerned that they had made a mistake as David had difficulty moving and recovering. For each expansion appointment they were required to drive almost 45 minutes. Additionally, it was important for David to complete physical therapy. However, within a couple of weeks after his initial surgery he was back to doing all of the things he loved including surfing, being outdoors and playing with his dog.



“Our commitment was making sure that we got him to his expansion appointments and his therapy appointments,” states David’s mom. “We knew these would help him get him back to where he was before surgery and get him strong again.”

Uncertainty Becoming More Certain

Dr. Michael Vitale and his patient, Michael McCabe

If you attended the debate session at ICEOS this last year you quickly realized that while there are obvious treatment routes for some patients, many times one clinician will choose a different treatment method than the clinician sitting next to him. In 2023, Dr. Michael Vitale published a paper to demonstrate, that while there is still some uncertainty in treatment methods across surgeons, over the past 10 years there has been a shift in treatment preferences with a consensus for a more conservative management upon initial treatment.

In this study, Dr. Vitale wanted to provide a 10-year comparison that re-evaluated consensus and uncertainty among treatment options for early onset scoliosis. 11 surgeons were invited to complete a survey of 315 idiopathic and neuromuscular cases (the same cases presented in 2010). Treatment options included the following: conservative management, distraction-based methods, growth guidance/modulation, and arthrodesis. Consensus was defined as $\geq 70\%$ agreement, and uncertainty was $<70\%$.



Consensus for conservative management was found in idiopathic patients ≤ 3 years old, whereas in 2010, some of the cases were selected for surgery. There is currently a consensus for casting idiopathic patients aged 1 or 2 with moderate curves, whereas in 2010, there was uncertainty between casting and bracing.

Presently, preferences for conservative management have increased in comparison to 2010, and casting appears to be preferred over bracing in select infantile cases. A patient of Dr.

Michael

Vitale, Michael McCabe, benefited from this research.

Little Michael was diagnosed with scoliosis at just 8 months old. Initially, it was decided to wait and watch his curve and when he turned one, casting treatment began. For the next year, Michael underwent four Mehta castings. After that year, he transitioned to bracing for the next two years. His mom states, “Throughout all this, Michael was still able to lead a normal lifestyle and be active in many different sports and activities. Some of his favorite hobbies include playing baseball, soccer, basketball and karate.”

After waiting a few years with conservative treatment, magnetic rods were inserted surgically to continue to correct his curve. Michael’s mom continues, “What helped us through this difficult time was knowing how skilled Dr. Vitale and his team were. We knew that Michael was in the best hands possible. His road to recovery was not without obstacles, but just two short months later he was back to his normal, active self on the baseball and soccer fields!”

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Throughout the Years: The Impact of PSSG on the Treatment of Scoliosis

From its inception in the early 2000's, the Pediatric Spine Foundation has maintained its vision to help children with spine problems live longer, better lives. Starting with two separate groups - the Growing Spine Study Group and the Chest Wall & Spine Deformity Study Group – these individuals were united in their vision to improve the quality of care and treatment options for patients and families with scoliosis, beginning their data collection in an excel sheet and eventually merging to create the largest children's scoliosis database in the world. This journey has left us reflecting on the past, engaged in the present, and excited for what the future holds for this community.

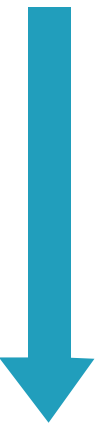
LEARNING FROM OUR

PAST ←

From 2001 - 2008, the only implant data that you would find in our registry would be for Traditional Growing Rods (TGR) and Vertical Expandable Prosthetic Titanium Ribs (VEPTR). For Braydon, one of the first VEPTR implant patients, this not only expanded his rib cage allowing his breathing to significantly improve, but also expanded his future possibilities that had been tucked away with his initial scoliosis diagnosis. The research that followed the first VEPTR implants was positive, as it was a completely new treatment, where before there hadn't been any options. With improvements in Cobb angles, thoracic height and Thoracic Insufficiency Syndrome (12, 15, 3), many surgeons were excited to learn how to utilize this treatment for their patients. With any new technology, however, it is also important to learn from the complications and issues that arise, with the vision and understanding that better technology is always on the horizon. With recurrences of device

migration, and the need for multiple surgeries, resulting in a higher risk for internal and external infections, these were clear signs that there was a need for something better (4).

ENGAGED IN THE PRESENT



In recent years, (2014 and 2019), the excitement in this community rose again as less invasive surgical options became available through the use of Magnetically Controlled Growing Rods (MCGR) and Vertebral Body Tethering (VBT). MCGR quickly surpassed the use of Traditional Growing Rods and by 2021, 99% of initial implants in our registry chose this instrumentation for their initial treatment (13). Patients and physicians alike were excited at the prospect of less surgery with similar or better results. Similar energy arose as VBT was approved by the FDA (14) and the possibility of no spinal fusion at all presented itself to some patients. With the multitude of questions that come with new treatment methods and technology, PSSG established two prospective research studies to provide further guidance on how to best utilize these implants (MCGR and VBT) in addition to multiple retrospective studies focusing on the unique nuances of each one. These include, but are not limited to, questions surrounding contraindications for MCGR implants, the positive psychosocial effects of MCGR implants (9), the effectiveness of VBT (11) compared to fusions and how BMI affects the outcomes of VBT (10). With over 50 projects underway, 15 research interest groups, and members around the world collecting data, every day brings us closer to answering the multitude of questions that influence our care and the best future for our patients.



ANTICIPATING THE



FUTURE

“The Pediatric Spine Foundation is proud, but not yet satisfied. The best is yet to come!”
- PSF President, Dr. Jack Flynn

As we stand on the shoulders of giants in anticipation of what the future holds, a recurring theme has been to “wait and watch”, encouraging many physicians to delay surgery as long as possible and begin with bracing or casting patients. While there have been studies showing the emotional challenges that accompany serial casting (7) and concerns with repetitive anesthesia, there is growing evidence of the positive outcomes that result from this treatment route. These include delayed surgery for many types of patients (5) as well as positive outcomes for casting patients with no anesthesia (6). PSSG is also working to seek out the best treatment methods through our prospective study on Casting vs. Bracing (16) as well as the multiple projects being produced by our Non-Operative Research Interest Group.

With each new technology, the Pediatric Spine Foundation learns more and is able to better treat our unique patient population. With unmatched dedication, continued collaboration with industry, and the passion of our clinicians, we will continue learning from the past, applying the most up to date treatment methods of today, and progressing toward a bright and hopeful future together. The best truly is yet to come!

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2002

GSSG starts collecting data



Brayden, one of the first VEPTR implants

2007

Vertical expandable prosthetic titanium rib for thoracic insufficiency syndrome: a new method to treat an old problem



2014

MCGR receives full FDA approval

2020

Serial casting for early onset scoliosis and its effects on health-related quality of life during and after discontinuation of treatment

Serial Casting in Neuromuscular and Syndromic Early-onset Scoliosis (EOS) Can Delay Surgery Over 2 Years

Awake serial body casting for the management of infantile idiopathic scoliosis: is general anesthesia necessary?

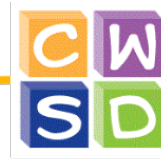
2022

Body mass index affects outcomes after vertebral body tethering surgery

Contraindications to magnetically controlled growing rods: consensus among experts in treating early onset scoliosis

2001

CWSD starts collecting data



2004

VEPTR HDE approval



2013

VEPTR to treat nonsyndromic congenital scoliosis: a multicenter, mid-term follow-up study

Wound complications of vertical expandable prosthetic titanium rib incision.

VBT receives HDE approval



2019

PSSG & GSSG merge, forming the largest children's scoliosis research database in the world



Database reaches 10,000 patients!



2021

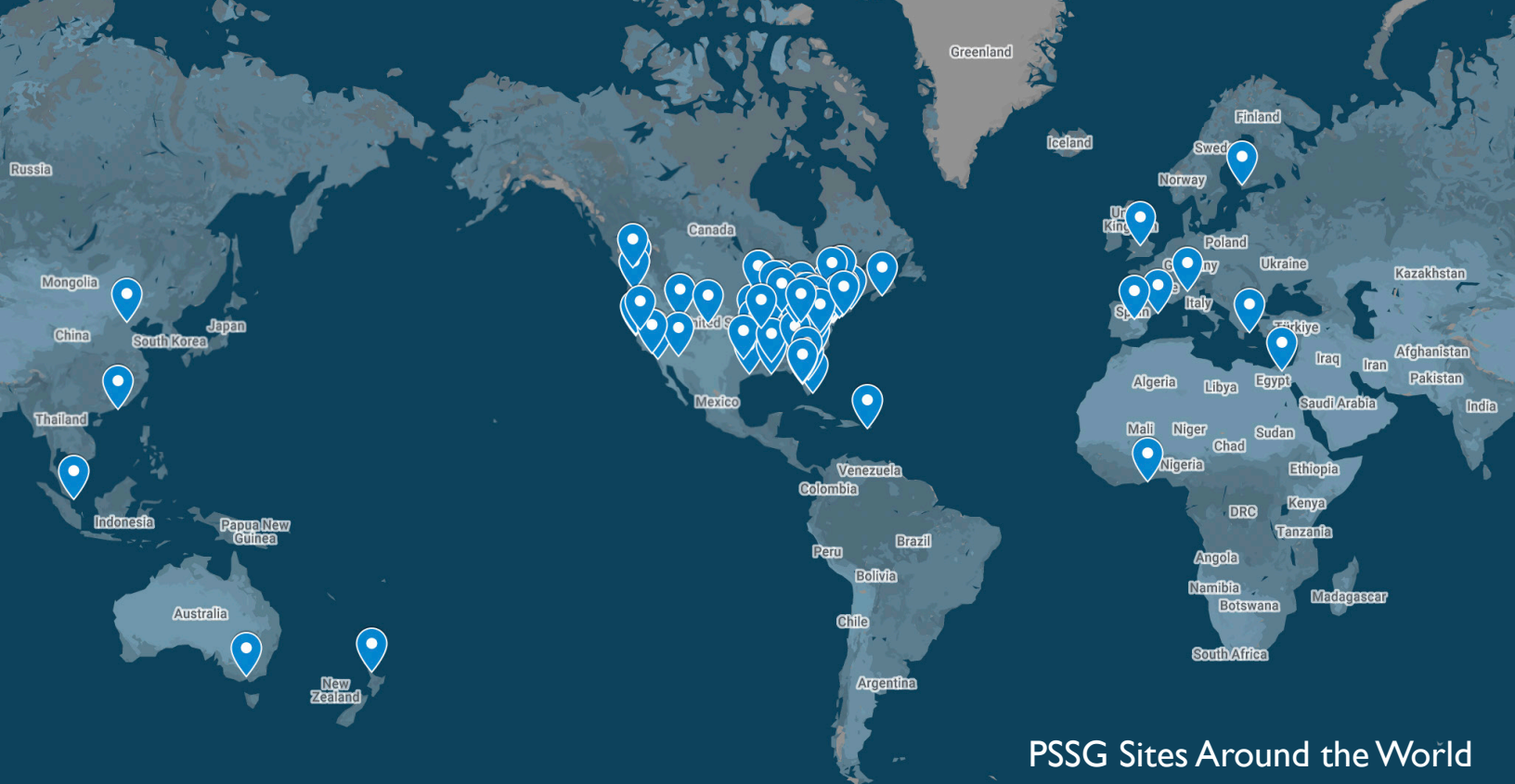
99% of initial implants are now MCGR



Comparing health-related quality of life and burden of care between early-onset scoliosis patients treated with magnetically controlled growing rods and traditional growing rods: a multicenter study

2023

A multicenter comparative analysis of spinal fusion and vertebral body tethering (VBT) for idiopathic scoliosis.



PSSG Sites Around the World

Member Donations & Acknowledgements

\$20,000+

Jack Flynn
Paul Sponseller

\$10,000+

Behrooz Akbarnia
Scott Luhmann

\$5,000+

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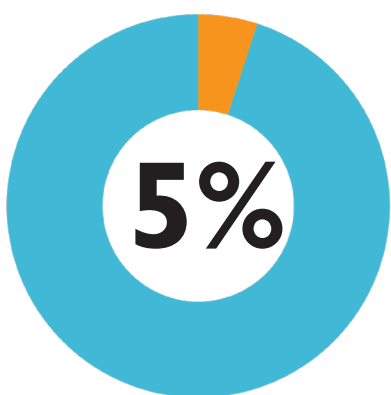
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\$500+

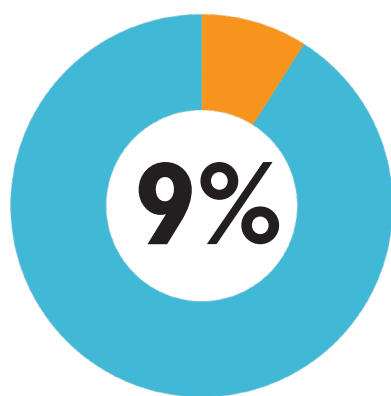
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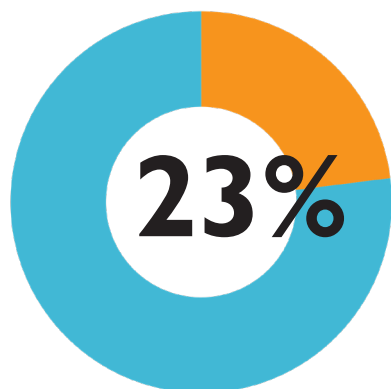
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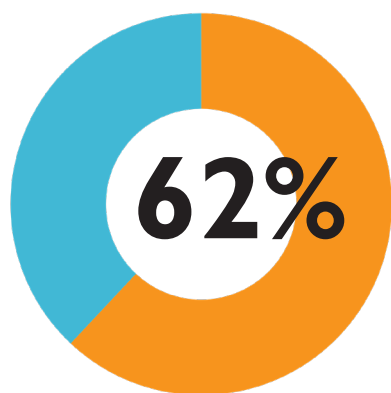
Database Infrastructure



Research Grants



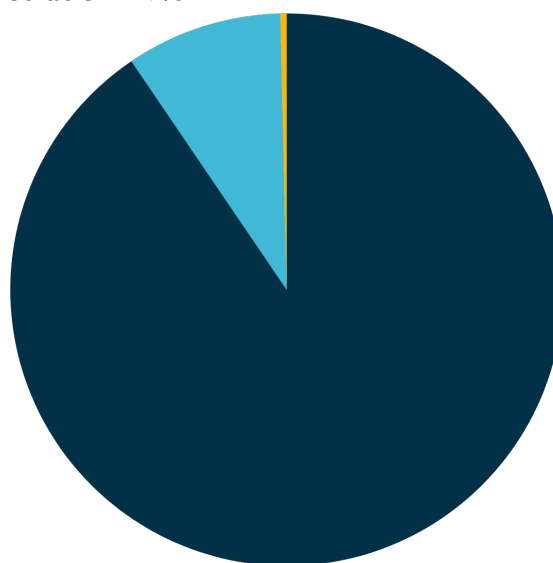
Education



Research & Publication Support

Administration - 9%

Fundraising - 1%



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.

Publications

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Thank You!

We thank all of those who continue to support our mission to help children with scoliosis live longer, better lives. We are excited for what we have been able to accomplish in 2023 and anticipate another great year ahead of us!

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