

2024



Annual Report



Pediatric Spine
Foundation



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A Message from our President

Paul Sponseller, MD

As we celebrate the progress made in 2024 it is important to bring vitality to the numbers that we hold in such high esteem - 13,400 patients, 56 projects underway, 29 publications, and 96 active sites across 13 different countries around the world. What is the actual impact of all these numbers? Thousands of patients enrolled into our registry is a number worth celebrating, but when we unveil the impact of that number it becomes significantly more meaningful.

To illustrate this, we must understand that 13,400 patients enrolled in our study registry is not just a data collection number, but represents thousands of individuals whose stories we have followed and learned from to help the future of EOS grow brighter. 56 projects in the works are providing answers to difficult questions that deliver guidance, education and hope for physicians and patients. 96 active sites across 13 different countries illustrate the worldwide reach of our membership, providing a community with passionate individuals that are hopeful for what the future might bring. In the end, what these numbers truly represent is the difference that can be made in one child's life as a result of the passion, innovation, and collaboration that supports our mission of helping children with spine problems live longer, better lives. As we move forward in this journey together I hope that we can celebrate these milestones but also recognize that our work is not yet complete. Our impact has the potential to shape the future, not just for our organization but for the countless children and families facing early onset scoliosis. I am immensely proud of what we have achieved together and I have no doubt that together we can leave an indelible mark on the lives we touch.

OUR IMPACT



Assessing the Long-Term Impact of VEPTR

Dr. Norman Ramirez-Lluch and his patient, Gabriela Rivera

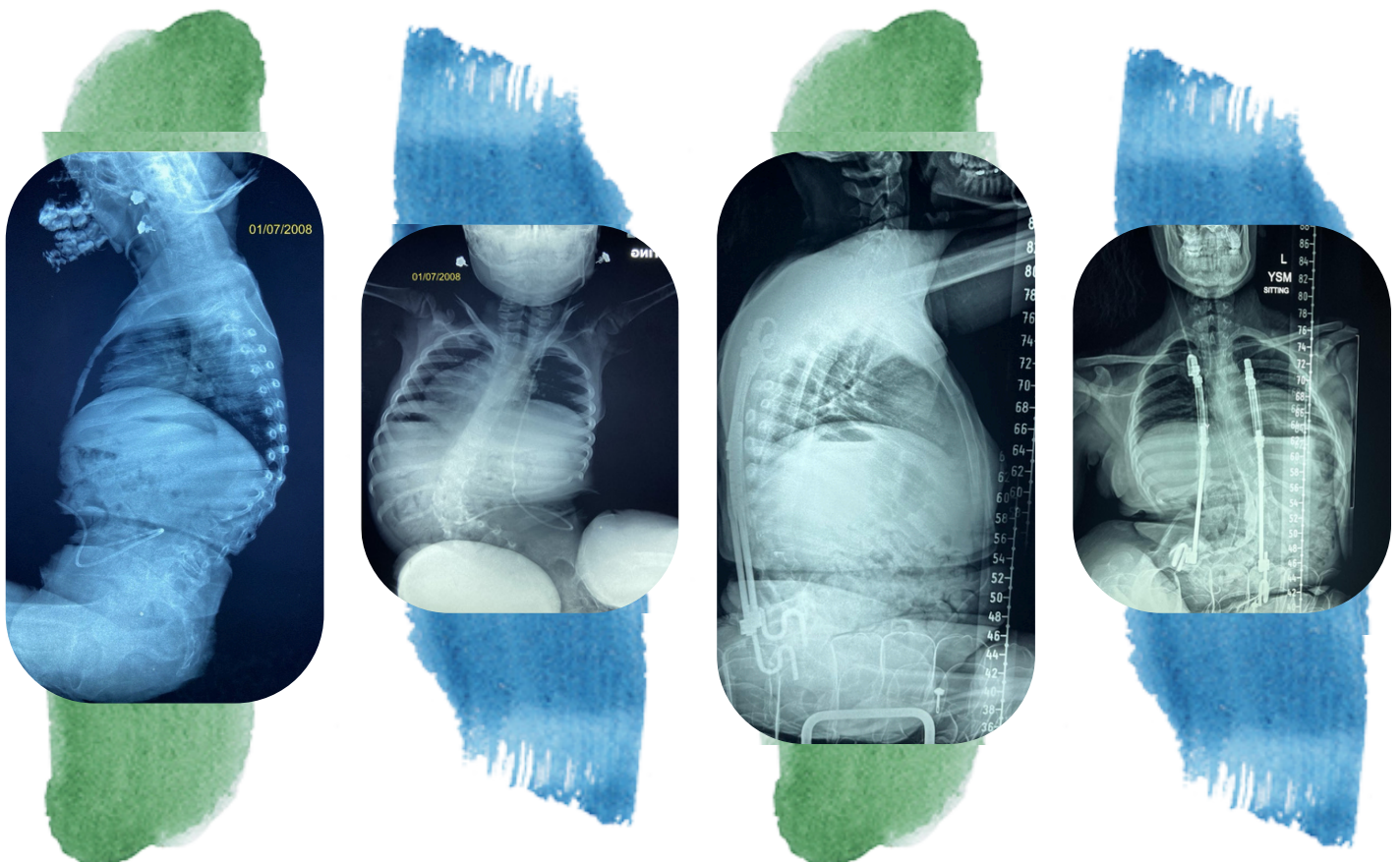
In 1989, an innovative project at CHRISTUS Santa Rosa Children's Hospital in San Antonio, Texas, introduced the Vertical Expandable Prosthetic Titanium Rib (VEPTR) device, designed to correct coronal deformities and stimulate thoracic spine growth while mitigating respiratory dysfunction. Its technique requires frequent expansion and lengthening procedures to correlate with average spinal growth. The standard practice for rib-based growth instrumentation was to lengthen every six months until patients reached sufficient maturity to undergo final fusion or to stop lengthening. The goal was to offer early onset scoliosis (EOS) patients a treatment that would enhance lung development by increasing thoracic space. However, the use of VEPTR implants has seen a significant decline as alternative surgical options emerge.

In this study, Dr. Norman Ramirez-Lluch and his team analyzed 447 patients from the Pediatric Spine Study Group (PSSG) registry, all treated with VEPTR surgery. The patients were followed for a minimum of five years, and the outcomes measured included spine growth, coronal correction, pulmonary function, complication rates, and health-related quality of life (HRQoL). This study presents

the most extensive sample of VEPTR utilization in the EOS literature, with a minimum of five years of follow-up. Although it fell short of preserving pulmonary function, the study revealed VEPTR successfully improved spine growth and most importantly coronal correction.

Gabriela Rivera, a young patient diagnosed with non-ambulatory myelomeningoceles, underwent VEPTR implantation at 8 years of age. Her family was initially concerned about the complexity of the surgery but noticed improvements in Gabriela's spine curvature and growth after the procedure. Over the years, despite facing complications, Gabriela was able to lead a rewarding lifestyle, which provided hope to her family. Currently, Gabriela continues to show improvements, and now is 22 years of age.

Nevertheless, Dr. Ramirez-Lluch's work highlights the importance of exploring alternative methods for treating EOS in terms of pulmonary function. "While VEPTR has played an important role in managing scoliosis in young patients, the medical community must continue innovating to find solutions that provide both spinal growth and respiratory function preservation." Dr. Ramirez-Lluch stated.



Do Neuromuscular Early-Onset Scoliosis Patients with Rib-on-Pelvis Deformity have decreased Reported Pain after Surgery?



Dr. Patrick Cahill and his 10 year-old patient

Non-ambulatory patients diagnosed with neuromuscular scoliosis can experience truncal weakness, resulting in the ribs on the concave side of the curve to rest on the high side of the patient's pelvis. This is referred to as a rib-on-pelvis (ROP) deformity and leads to significant pain for the child affected by this condition. Dr. Patrick Cahill sought to investigate the level of reported pain in patients prior to and post-surgical intervention to correct this deformity.

In this study a total of 44 patients with neuromuscular ROP scoliosis were compared to 63 control neuromuscular scoliosis patients who were treated from 2012-2021. Pain was assessed using the Early Onset Scoliosis 24-Item Questionnaire (EOSQ-24) at the pre-operative, immediate post-operative, and 2-year post-operative timepoints. Patients with the ROP deformity were observed to have a significantly higher reduction in pain severity and frequency two years after surgery compared to patients without ROP.

While the decision to undergo surgical management is significant and can be a burden, this research can provide families with evidence that many patients with ROP have experienced a significant reduction in pain following surgery. One such example is a 10-year-old female diagnosed with Cerebral

Palsy with GMFCS V that has been under the care of Dr. Cahill since she first presented to his clinic at the age of 3. Under Dr. Cahill's care she was braced, but as her deformity progressed, she underwent growth-friendly intervention, before receiving a definitive T2-pelvis fusion. While Dr. Cahill's experience taught him that this girl would likely see improvement in her pain associated with ROP, scientific data to support this assertion was missing. This made it more difficult for her family to make the decision to proceed with surgery. Ultimately, they chose surgery. This case inspired Dr. Cahill to work with the PSSG to try to answer important questions about the impact of ROP on pain and whether surgery could help. Following treatment, this patient had her ROP deformity corrected, experienced decreased pain, gained the ability to sit up independently for longer periods of time, and was eventually weaned off nightly respiratory support. Dr. Cahill anticipates that following recovery from her recent fusion, she will be able to resume the activities that she loves including family trips to the ocean and pool-based therapy.





ICEOS 2024

Scottsdale, Arizona

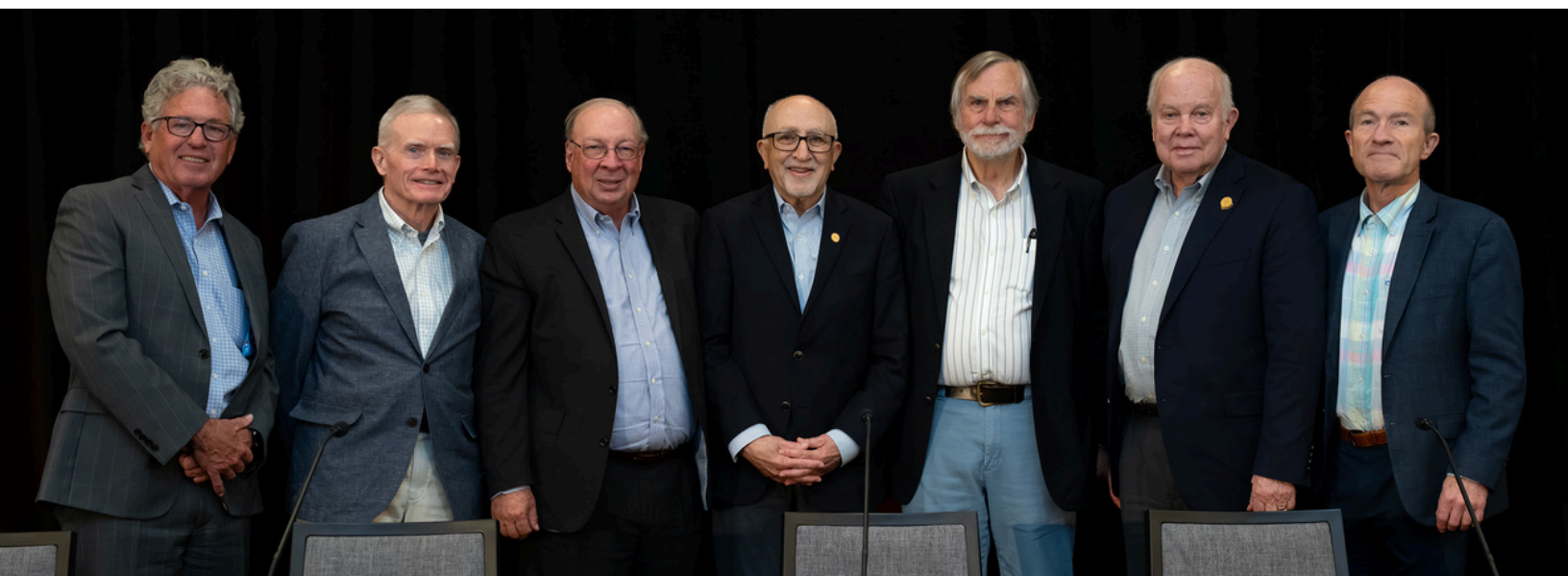


Chair: Ron El-Hawary, MD

Co-Chair: Ying Li, MD

The 18th International Congress of Early Onset Scoliosis and the Growing Spine is now but a fond memory. From November 13-15, 2024, participants and faculty from around the world gathered at the Scottsdale Resort at McCormick Ranch in Arizona. The meeting's theme of "past, present, and future of pediatric spine deformity" drew a record number of attendees who engaged in lectures, workshops, small group sessions, and 52 scientific podium presentations.

The meeting started with a session focused on "the past" and included a panel discussion with several legends in our field, including Drs. Behrooz Akbarnia, John Emans, George Thompson, John Smith, Charlie Johnston, Doug Brockmeyer, Greg Redding, Randy Betz, and Rene Castelein. Grant Hogue and Rob Murphy led this first-of-its-kind interactive and entertaining discussion on the early days of pediatric spine deformity.





The Smith Family Lecture was given by Stephen Murphy, a Special Agent with the Drug Enforcement Administration (DEA), who told us how he and his partner, Javier Peña, targeted the world's first narco-terrorist and the Medellin Cartel. His inspirational talk on teamwork and leadership was a phenomenal way to kick off the social aspect of the meeting.



The Campbell Award honors a physician or scientist for outstanding contributions to the care of children with early onset scoliosis, in honor of the late Robert M. Campbell Jr, MD. This year's well-deserving recipient, Dr. Charlie Johnston from Dallas, Texas was a founding member of the Pediatric Spine Foundation and his contributions have certainly shaped the past, present, and future of our field. Dr. Ferran Pellisé, director of the Barcelona Spine Institute was one of the founders of the European Spine Study Group and was one of the earliest surgeons to apply artificial intelligence to spine surgery. He inspired us all to look into the not-so-distant future with his Keynote Address "Artificial Intelligence in the Evaluation and Treatment of Spine Deformity."



This year's meeting has been a success and is now viewed not only as the premier meeting to learn about early onset scoliosis but also to learn about all pediatric spinal conditions including spondylolisthesis, cervical spine, spine tumors, and neurosurgical spine conditions. Be sure to attend next year's meeting, led by Drs. Ying Li and Scott Luhmann, in Cannes, France!

PSF Travel Grant



Dr. Denis Sakai
Sabará Children's Hospital
Brazil

Hi! My Name is Denis Sakai. I am an orthopedic surgeon, born and raised in São Paulo, Brazil. Eighty percent of my practice is dedicated to the pediatric spine, half of them are early onset patients. For every young kid with a spine deformity that I see, I question what would be the correct answer for the spine, for the lungs, for the parents and for myself. I attended my first ICEOS meeting in Rome, 2022 (and I did return in Charleston, 2023). ICEOS changed my mind in 2 different ways: I could see that the dilemmas and questions were quite the same as mine all around the world and most importantly, the tireless search for the correct answers should be the cornerstone for every surgeon treating these kids.

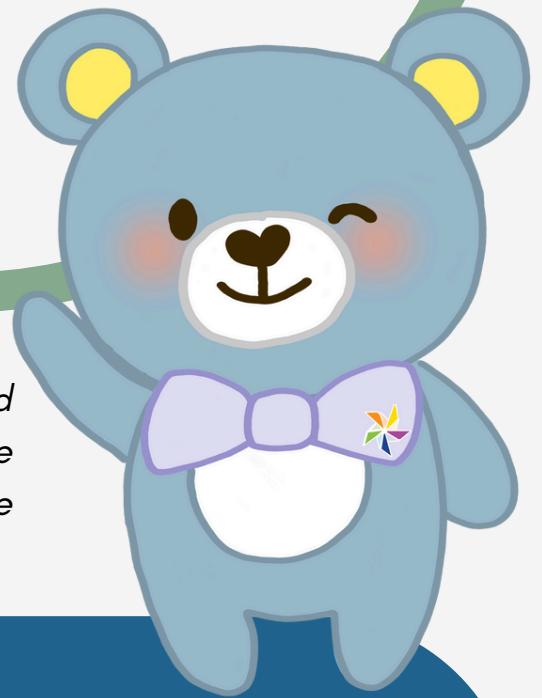
In my country we do not have dedicated clinics or hospitals to EOS patients. In 5 years I hope I can build a multidisciplinary team to take better care of these kids and I look forward to contributing to the PSSG database as a Latin American center in the near future.



Research Grants

Did you know that you can apply for a PSSG research grant? Check out our currently funded projects that are underway!

For the 2024 cycle, we received 14 letters of intent and we invited 8 PIs to submit full grant applications. These grants focused on a variety of topics including the following categories:



Improving VBT materials

Determining intraoperative VBT correction

Pediatric spondylolysis

Automated radiographic measurements

Brace development for neuromuscular spine deformities

Lung clearance index to monitor lung function

Validating uniplanar axial rotational measures

Apical intervertebral disc changes

Part-Time Bracing in Juvenile Idiopathic Scoliosis – A Multicenter Prospective Study

Benjamin Roye, MD



Dr. Roye and his research team are conducting a multicenter research initiative to investigate the comparative efficacy of part-time bracing versus observation in the management of JIS, a condition typically affecting children aged 4 to 10 years. Their 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, they plan to identify patient and brace characteristics that might be predictive of permanent correction of the spinal deformity.

Developing a Frailty Model to Identify Pediatric Spinal Deformity Patients At-Risk for Prolonged Hospital Stay

Michael Vitale, MD

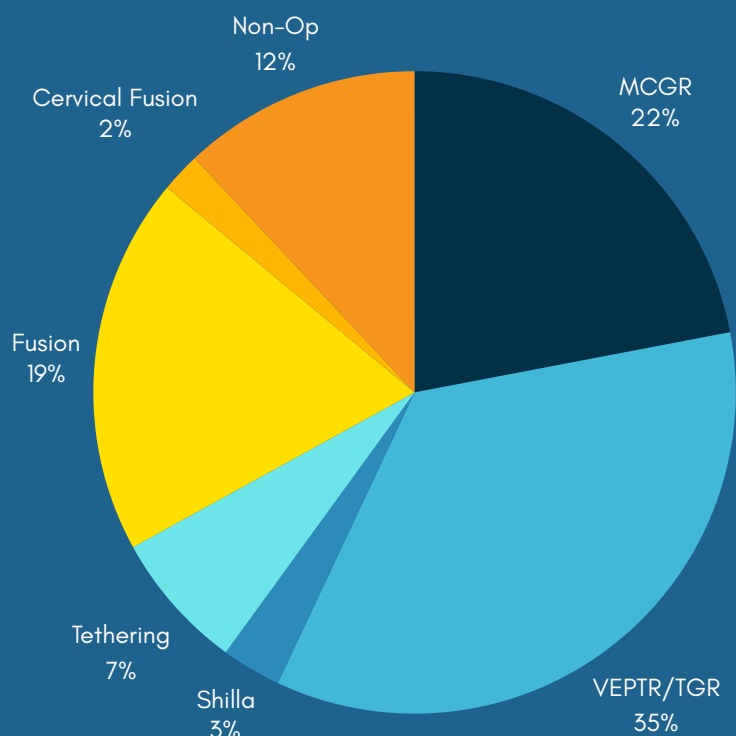


The primary goal of this study is to develop a frailty score for patients with EOS using available pre-operative risk factors and intra-operative variables using machine learning. Their site has obtained IRB approval and developed a machine learning (ML) risk model that uses gradient boosting algorithms to predict the likelihood of frailty in individuals based on health and demographic factors such as age, BMI, comorbidities, mobility scores, and nutritional status.

Six-Minute Walk or Push Test in Children with Early Onset Scoliosis

Amy McIntosh, MD, Karina Zapata

The purpose of this multicenter study is to determine reference values of 6MWT/6MPT scores in children with EOS and to assess for demographic factors (such as age, biologic sex, body mass index, insurance type, area deprivation index scores), curve magnitude, PFTs and quality of life (EOSQ) associated with 6MWT scores.



Unique Patients Used in Studies by Primary Treatment

Roughly 5,500 patients were included this year in studies with the majority being VEPTR/TGR.

Let's Travel the World with PSSG



At FOCOS, we treat a diverse range of pediatric patients with various forms of scoliosis, including neuromuscular, idiopathic, congenital, syndromic, post-TB kyphosis, and others. Our team includes Professor Ohenaba Boachie-adjiei, Dr. Kwadwo Poku Yankey, and Dr. Arthur Sackeyfio.

Our patients come from different countries including Ghana, Ethiopia, Sierra Leone, Nigeria, Kenya, Uganda, and DR Congo. However, the majority of our patients are from Ghana and Ethiopia.

Our PSSG program at this site consists of 116 patients, comprising 52 males and 64 females. Currently, 106 patients are actively receiving treatment while 1 has unfortunately passed away. 4 patients have completed their treatment and have aged out of the program, and we are currently unable to locate 5 patients for follow-up appointments.

One of the primary obstacles patients face is financial hardship, which often hinders their ability to undergo surgery. In fact, many patients require financial assistance to access surgical interventions. Another significant challenge is adhering to follow-up visits, particularly among patients with MGCR. The majority of these patients struggle to attend the regular 3-months check-ups for lengthening procedures due to financial constraints.

FOCOS Hospital

**Joined PSSG
in 2019**

**116 patients
enrolled**

FOCOS offers a range of orthopedic surgical specialties, and patients undergoing surgery typically go through three distinct phases: pre-operative, intra-operative, and post-operative. During the pre-operative phase, researchers have the opportunity to recruit patients into PSSG and administer questionnaire tools. Patients with severe spine deformities may also be placed in Halo Traction for extended periods of time, a unique opportunity offered in this part of the world by FOCOS. After traction the patients may go on to have definitive surgeries like a posterior spinal fusion or have growing rods.

I am Donald Agyekum. I love to play football. I first visited FOCOS Hospital on 23rd November, 2020 at the age of 3. My mother realized a curve at my back and decided to take me to see the doctor. We met Dr. Kwadwo Poku Yankey. He took his time to explain how these curves develop in the spine. After examining my x-rays, I was diagnosed with Infantile Idiopathic Scoliosis. Finally, when we finished with the discussion, I got to understand that, I will need surgery to correct this curve. However, because I was still young, I would have surgery for growing rods. Subsequently, on 13th April, 2021, I had surgery for MAGEC Growing Rods, PSF T1-L3. Surgery was uneventful. I lost about 100ml of blood. I stayed at the ICU for a day and then I got discharged to the ward.



After my surgery the nurses were very friendly and caring. I loved their services. I hardly missed my mom. I finally got discharged on 18th April, 2021. Post-discharge, I was scheduled for a post-op outpatient visit six weeks later. After my initial visit, I was asked to visit in 3 months time, where I would have my first lengthening procedure. Subsequently, on 12th July, 2021, I was lengthened 3mm bilaterally for the first time.

Currently, I am 3 years and 4 months post-surgery, and I am doing well and I love the entire process. I would like to let everyone know that scoliosis is treatable. No one should panic when surgery is suggested to them. I highly recommend FOCOS hospital to anyone with spine deformity. They are the best!



Dr. Ron El-Hawary sees pediatric spinal deformity patients from birth to 19 years of age. In addition to treating adolescent idiopathic scoliosis (AIS) and neuromuscular scoliosis patients with traditional techniques, he also offers fusionless surgeries, including vertebral body tethering and posterior dynamic distraction, for patients with AIS. He is passionate about treating young patients with scoliosis and about improving their quality of life during their early onset scoliosis journeys.

The biggest challenge that this health center has is timely access to care. With only two pediatric orthopaedic spine surgeons in this region of Canada, the waiting lists for patients to be seen in clinic and for their ultimate surgeries are longer than our team would like. We have recently been successful in obtaining more resources, including the addition of a third pediatric orthopaedic spine surgeon, Dr. Kevin Morash, who will also be involved with PSSG.

IWK Health Centre

**Joined PSSG
in 2008**

**220 patients
enrolled**

From the Physician's Perspective: In 2008, at the age of 20 months, Natalya was the first patient from Canada that was enrolled in the Pediatric Spine Study Group (previously known as the Chest Wall and Spine Deformity Study Group). With a diagnosis of idiopathic early onset scoliosis, Natalya's treatment journey started that year with VEPTR (vertically expandable prosthetic titanium ribs) surgery that required multiple elective lengthening procedures in the operating room. In 2019, she had successfully completed her growth friendly surgery and "graduated" to a spinal fusion surgery.

Natalya and her loving family would like to extend their thanks to the PSSG, Dr. El-Hawary and to Nurse Karen for their commitment to providing the best care possible for her.



Starship Children's Hospital is the only children's hospital in New Zealand serving a population of approximately six million people. We have grown from having two spine surgeons, Dr. Michael Barnes and Dr. Haemish Crawford in 1999, to now having four pediatric spinal surgeons. We are all Fellowship trained having worked with Dr. Stuart Weinstein (University of Iowa), Dr. Sean Molloy (Stanmore Orthopaedic Hospital, Stanmore,

**Starship
Children's
Hospital**

**Joined PSSG
in 2022**

**54
patients
enrolled**

London), Dr. Andrew Cree (Sydney, Australia), Drs. Vitale, Lenke, and Roye (New York-Presbyterian/Columbia) and Dr. Firoz Miyanji, (Vancouver Children's Hospital). We therefore have a very broad experience with lots of different approaches and can offer the full range of paediatric spinal surgery from the occiput to the coccyx. We have a dedicated spine theatre with full navigation systems, high tech imaging and spinal cord monitoring. We have two specialist nurse practitioners who work with us, and we have Dr. Nicola Wilson, a fully trained orthopaedic surgeon, who is in our spine department. She is nonoperative but looks after a lot of our follow up patients and nonoperative patients. We were initially in the Growing Spine Study Group and then when this merged with the PSSG, we became more active. It was not until 2017 that we had Emanuela Crua, an orthopaedic surgeon from Italy, join us as our research coordinator. She is instrumental in keeping the wheels rolling.

Our main problem with enrolling patients is encouraging the nurses in clinic to help us with this. We are presently seeking another nurse to help us enroll patients. I think this is crucial as in our very busy clinics, we really struggle with the time to sit down and talk to patients about the whole study group and appreciate someone helping us with that. Once we have this new appointment, I am sure our recruiting will increase dramatically.

Hi - I'm Zac's mum, he has given me permission to write this; he is currently recovering from his spinal fusion and will not consider doing anything that feels like homework!

Zac is 15 years old and from Auckland, New Zealand. He loves sport and PE and his two favourite sports are cricket and football. He enjoys the beach and is pretty good at skim-boarding and also does a bit of surfing too. Zac enjoys video games and plays on a PC that him and his dad built from scratch.

Our family consists of mum, dad, Zac and his older sister Amelia. Zac is year 11 and attends Northcote College – he enjoys history and English but won't admit to liking school apart from hanging out with friends (and sport).

At the 20 week ante natal scan, we found out that Zac had a curve to his spine and we then had to see a fetal specialist for more tests. The specialist turned out to be Mr Crawford's next door neighbour and he called Haemish who was able to come and chat to us. I had worked with Haemish at Starship Hospital and it was very reassuring to be able to talk to him straight away.

Although further scanning did not reveal much more, we didn't really know what else to expect when Zac was born. The main thing that was noted at birth was a sacral dimple but everything else seemed fine.

In the next few weeks and months, Zac had multiple health issues and he was diagnosed with VACTERL association. As well as the spinal abnormality, he had an H type rectal/urethral fistula, a tethered spinal cord, tracheomalacia & laryngomalacia and a heart murmur. Despite a lot of hospital admissions and a few different surgeries, especially in the first year of life, Zac thrived and developed normally. His VACTERL was classed as mild but if Zac had been our first child, I wouldn't have had any more – way too stressful, even though I'm paediatric nurse!

Haemish has been involved in monitoring Zac's spine his whole life. He has had six to twelve monthly xrays and follow ups and in about April 2024 the xray showed the curvature had changed from about 40 degrees to about 65 degrees. This change had occurred in six months since the previous xray. Zac had also noticed some changes; his right shoulder was much higher than the left, he had pain and trouble sleeping at night. It was time to discuss surgery which we knew was a high probability. As well as discussing this with Haemish, Tina the nurse specialist also met with us too, so we



knew what to expect. For Zac, the best bit of news about having the surgery was that he would be taller, at least 2cm taller immediately. Zac's dad and sister are both nearly 6ft tall and it was his goal was to be as tall as them post op, and then overtake them as he would hopefully continue to grow. On October 1st, Zac had a posterior spinal fusion. It was a long 7.5 hour wait for us and it was great to receive a phone from the theatre nurse at about 6 hours into the surgery to say all was going well, it was just taking a bit longer than expected. Zac did really well post op although it took a day or two to get his oral pain meds right. Once that was sorted, he was able to come home day four post op. Zac was really pleased to get home but he missed the hospital electric bed and found it difficult to get comfortable in his own bed for the first week.

So we are about 2.5 weeks post op now and things are going well. Still early days and Zac knows that he'll have to take it easy over the summer. He may not be able to play cricket but has got plans to learn how to score so he can still be involved. I have asked Zac what advice would he give others? "Take your pain medication" he says and although the first few days are hard, things will get easier.



Drs. Jason Cheung, Kenny Kwan, Paul Kojonen, and Graham Shea represent the Hong Kong PSSG site. The patients they see include different types of scoliosis like early-onset, juvenile, adolescent and idiopathic scoliosis. Others also include neuromuscular scoliosis, SMAs and NF-1 cases, etc. They mostly face difficulties in coordinating post-operative care in ICU and discharge planning for our patients. This facility is not yet a dedicated children's hospital in Hong Kong, which means that not all the care we provide is specifically tailored to the pediatric population of the entire region.

Hong Kong
University

Joined PSSG
in 2019

76
patients
enrolled

I am Hiu-ying, a local Hong Kong year 10 high school student. I enjoy playing mobile games during my free time, but I am very fond of connecting with my friends. I much prefer this over social media networking.

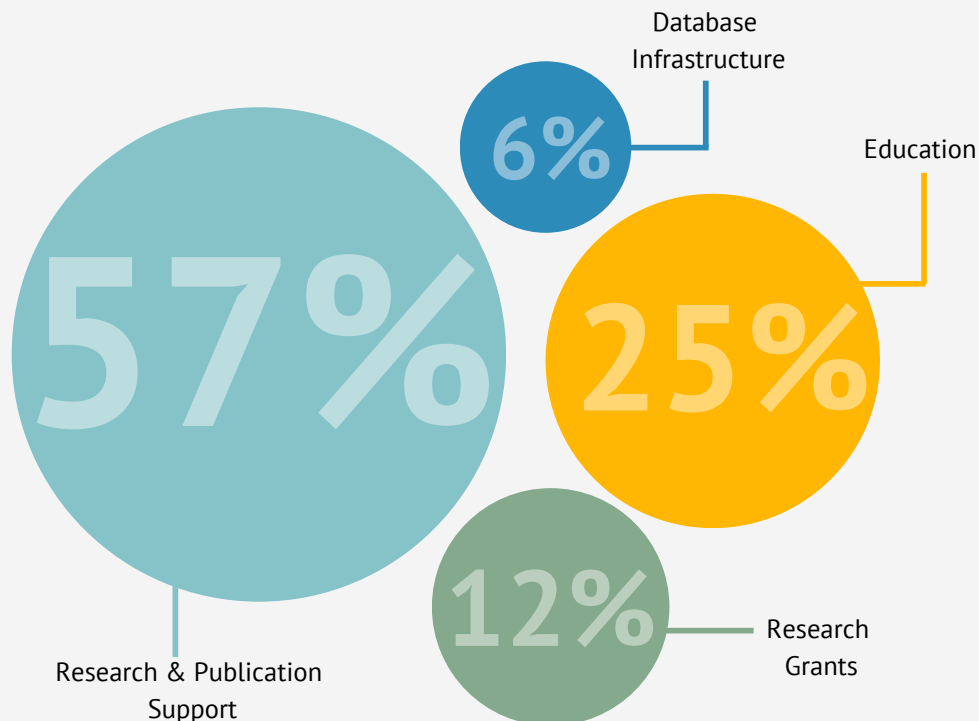
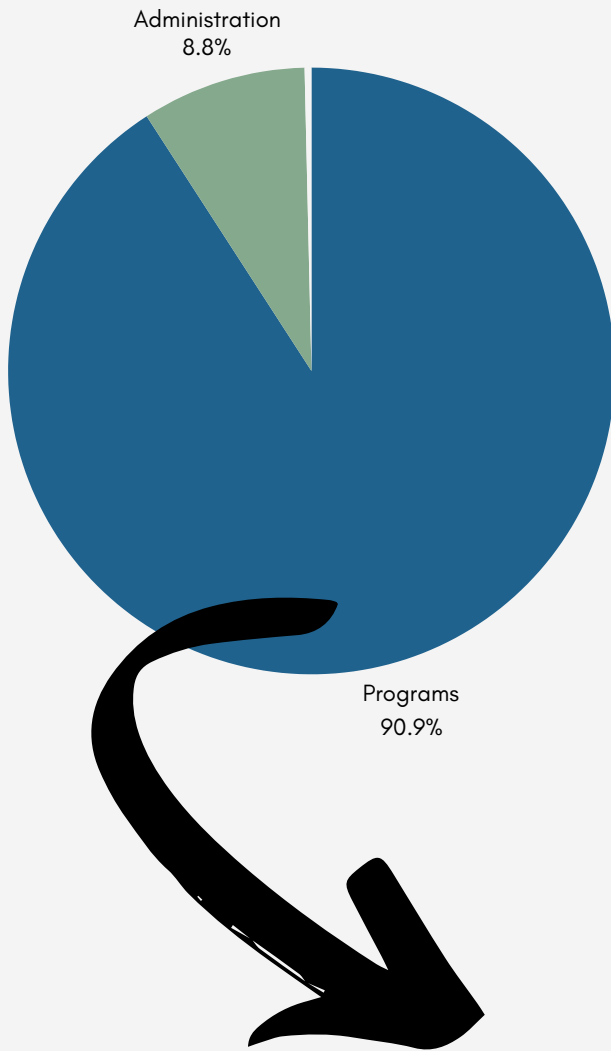
In the summer of 2019, I was diagnosed with adolescent idiopathic scoliosis and received treatment at a public orthopedic hospital. I underwent a Vertebral Body Tethering surgical procedure, followed by bracing to prevent further deterioration of my scoliosis curve. I am incredibly thankful for my parents' loving support throughout this journey, as well as for the orthopedic surgeon and nurses who played a crucial role in my care.

I believe that scoliosis treatment is an ongoing process that requires consistent adherence to doctors' guidelines. This approach can make the journey more manageable and lead to promising results .



Financials

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 & Presentations

Publications

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