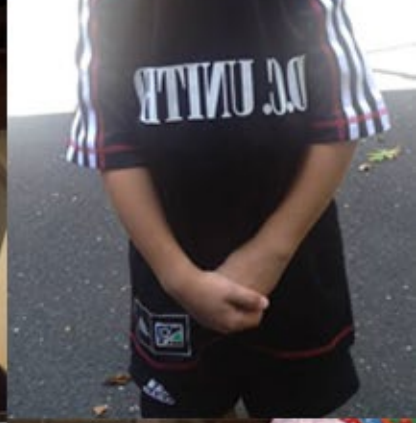




CHILDREN'S  
**SPINE**  
FOUNDATION

2013  
Annual Report



# A MESSAGE FROM THE BOARD OF DIRECTORS

It has been an exciting year of growth and change for the Children's Spine Foundation. The biggest and most obvious change was our name. Formerly the Chest Wall and Spine Deformity Research Foundation, we are now the Children's Spine Foundation. While our name has changed, our mission has not. Since 2005, we have been dedicated to helping children dealing with spine deformity live longer, better lives. As the Children's Spine Foundation, we will continue this commitment.

While a name change is a simple thing, it represents so much more. It builds on our strong history of groundbreaking research. It allows us to continue to support worldwide education. It incorporates the children that we work so hard to help.

Throughout this report, you will see evidence of our successes in 2013. We partnered with three new institutions, Mayo Clinic, Children's Hospital of Wisconsin, and Orlando Health, published 9 articles in peer reviewed journals, and hosted research meetings to further our study of early onset scoliosis. Much of this work was accomplished due to support from DePuy Synthes, a strong partner since our inception. We launched a Families In-Need program due to a generous gift from Mr. Hansjörg Wyss allowing us to profoundly expand our initiatives.

You will read stories of member accomplishments. You will meet a few of our patients who will share their inspiring journeys with you. You will see the incredible difference we are making in improving the lives of children dealing with complex spine deformity.

Thank you for supporting us in 2013. Together we are...the Children's Spine Foundation.

Sincerely,



Randal Betz, MD



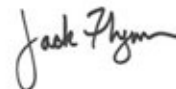
Steve Schwartz



Ron El-Hawary, MD



John T. Smith, MD



Jack Flynn, MD



Michael Vitale, MD MPH



**we  
are**

**PATIENTS**

# Patient Grants

The Children's Spine Foundation helps children diagnosed with complex spinal deformities gain access to necessary medical care. There are many different treatments available and it can be a confusing and difficult time for families struggling to deal with early onset scoliosis.

In 2013, we launched the Families In-Need program. This program was created with the specific purpose of helping families with financial challenges access medical care. We are working with family support networks to spread the word and have begun to improve access to comprehensive care for our most complex patients, both in the US and abroad. From Peru to Salt Lake City, from New York to Nigeria – we are helping families access the medical care they need. It is an exciting endeavor and our families are so grateful to obtain the support they weren't sure was possible.

For more information, and to download the Families In-Need grant, please visit:

[www.childrensspinefoundation.org/\\_pdf/grant.pdf](http://www.childrensspinefoundation.org/_pdf/grant.pdf)



## Sofia's Story

Sofia was diagnosed with progressive infantile scoliosis when she was 2 years old. Over the next two years, Sofia's family searched for the best treatment for their daughter. After much research, they discovered Mehta casting. Sofia's family lives in Lima, Peru where this treatment is not yet properly understood and available. Because of this, they reached out for help.

The Children's Spine Foundation provided funding for Sofia to travel to the US to receive proper care from a trained surgeon. The next step is to continue to support international training so that surgeons throughout South America are effectively trained in techniques to treat early onset scoliosis.



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**EDUCATION**

# Education

Our website ([www.childrensspinefoundation.org](http://www.childrensspinefoundation.org)) is the “go-to” site for education about Early Onset Scoliosis. Our members collaborated and created a section for both Families and Clinicians to learn more about the disease and to determine their treatment options.

## Q&A

John Heflin, MD  
Primary Children’s Hospital

### What is scoliosis?

All spines have curves. When viewed from the side, some curvature in the neck, upper trunk and lower trunk is normal. Humans need these spinal curves to help the upper body maintain proper balance and alignment over the pelvis and to cushion the brain from being jarred with each step. However, when there are abnormal side-to-side curves (when viewed from the front or back) in the spinal column, we refer to this as scoliosis.

### What is early onset scoliosis?

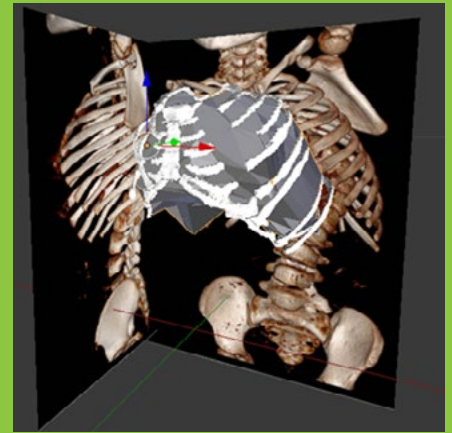
Early onset scoliosis is noticed prior to the age of 10. Children with early onset scoliosis have spines that still need to grow. In children with early onset scoliosis, care must be taken to provide a treatment that will control the progression of deformity while also allowing the spine to grow.

### What kinds of early onset scoliosis are there?

There are several sub-categories of early onset scoliosis that are commonly recognized. Included are idiopathic, neuromuscular, syndromic, congenital, as well as scoliosis associated with tumors, infection, prior surgery or trauma. **Congenital scoliosis** is associated with the abnormal formation of the spinal vertebrae themselves. This can also include the ribs which can lead to problems with lung development. **Syndromic scoliosis** is associated with specific underlying syndromes and genetic conditions. **Neuromuscular scoliosis** is an abnormal curve associated with injury or disease of the central nervous system. **Idiopathic scoliosis** simply means that we do not yet understand the cause of the abnormal curvature of the spine.

*For more information on treatments for early onset scoliosis, please visit our website at:*

[www.childrensspinefoundation.org](http://www.childrensspinefoundation.org)



## Educational Support

We also support education in the area of new technology. In 2013, we supported a groundbreaking research project which advanced our ability to educate about the growing spine.

### [Quantitative Thoracic Volume Modeling of Growing Spine Intervention](#)

The project, lead by Dave Polly, MD at the University of Minnesota, aimed to determine the change in thoracic volume before and after scoliosis correction and the correlation between pulmonary function and thoracic volume. Using a computer program designed by the research team, the 3-dimensional size of the chest was modeled from AP and lateral X-rays. This model allows lung volume to be measured in patients with early onset scoliosis.



**we  
are**

**RESEARCH**



# Research

In 2013, 489 new patients were enrolled into the Children's Spine Foundation Early Onset Scoliosis database. There are now 2,106 patients that are being followed at 24 participating medical centers. Over 10,000 patient visits and progress reports have been entered.

This valuable data is used by researchers around the globe to conduct studies that improve the life of children dealing with early onset scoliosis.

## Quality of Life and Pulmonary Function in Patients with Spinal Muscular Atrophy

Spinal Muscular Atrophy (SMA) is a genetic neuromuscular disease that causes muscle weakness and affects approximately 1 in 6000 babies born. David Roye, MD from Children's Hospital of New York, is leading a study that aims to determine the long-term effects of growing instrumentation on children with SMA as determined by pulmonary function testing and quality of life as measured by EOSQ-24.

## Hemoglobin as a Surrogate to Pulmonary Function

Pulmonary problems are common in patients with early onset scoliosis. Patients may have issues with respiratory function, increased bouts of pneumonia, or exhibit a decreased ability to run and play. For a variety of reasons, it is difficult to quantify these problems through pulmonary function testing. Because of this, researchers hope to find other methods to quantify a patient's pulmonary function. Michael Glotzbecker, MD from Boston Children's Hospital, is leading a study that aims to show that hemoglobin can be used to indicate pulmonary function in patients with early onset scoliosis. The study hypothesizes that patients with early onset scoliosis have night time hypoxia (low oxygen) and that hemoglobin can be used as a surrogate after adjusting for other factors. He also hopes to show that intervention with a surgical growing system such as VEPTR will decrease hemoglobin in patients with elevated levels preoperatively. There are 26 patients who were screened for this study in 2013. 8 of which had elevated hemoglobin.

## VEPTR in Early Onset Scoliosis without Fused Ribs

The VEPTR device, developed by Drs. Bob Campbell and Melvin Smith, is used to treat patients with signs of Thoracic Insufficiency Syndrome. The objective of this study, lead by Jack Flynn, MD, of Children's Hospital of Philadelphia is to evaluate the use of VEPTR in the treatment of children with progressive scoliosis without rib abnormalities. It is a prospective, non-randomized, multicenter study. There are currently 96 patients enrolled in the study.



## Research Spotlight

Dr. Michael Vitale received the award for best paper at the 7th International Congress for Early Onset Scoliosis held in November in San Diego, CA. Funding for this paper was provided by the Children's Spine Foundation.

[The Classification for Early Onset Scoliosis \(C-EOS\) Identifies Patients at Higher Risk for Complications at 5 years of Follow Up](#)

Michael G. Vitale, MD, MPH; Howard Y. Park, BA; Hiroko Matsumoto, MA; Tricia St. Hilaire, MPH; Jeff B. Pawelek, BS; Evan P. Trupia, BS; Hasani W. Swindell, BS; John M. Flynn, MD; David L. Skaggs, MD; David P. Roye, MD



# Our Mission

To help children with spine problems  
live longer, better lives.



**The Children's Spine Foundation is proud to support the Children's Spine Study Group.**

**The Children's Spine Study Group is performing an enormous amount of research in the area of early onset scoliosis.**

**Study Group research provides the basis for children with complex spine deformity to live longer, better lives.**

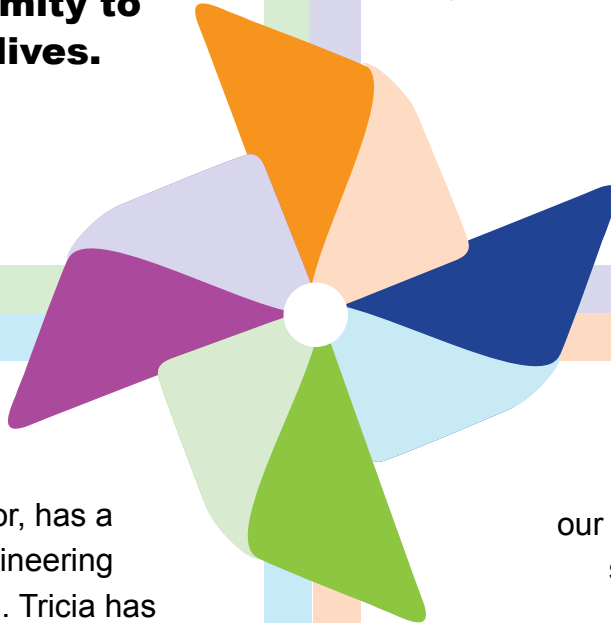
### **Study Group Facts:**

\*comprised of 42 experts in the field of early onset scoliosis

\*presented 230 scientific abstracts at major society meetings

\*published 80 publications in peer reviewed journals

\*leading 80 active projects in field of early onset scoliosis



### **Foundation Director**

Tricia St. Hilaire, the Foundation's Executive Director, has a background in Biomedical Engineering and a Masters in Public Health. Tricia has led the Foundation since its inception in 2005. Together with the Board of Directors, she ensures that the Foundation's limited funding is allocated in ways to make the biggest impact on families dealing with early onset scoliosis. Whether through meaningful research, direct family support, or educational initiatives, Tricia

ensures that the mission of the Children's Spine Foundation shines through in everything it does.



### **Our Dedicated Staff**

With minimal overhead, our talented team is responsible for supporting research, education, fundraising, and grants.

Tricia St. Hilaire - Executive Director  
Tara Flynn - Director of Reporting/ Analytics  
Sarah Mumford - Administrative Director  
Lan Torii - Radiographic Measurement



# BOARD OF DIRECTORS



**Randal R. Betz, MD** is a founding member of the Children's Spine Foundation and a current member of the Board of Directors. His leadership and vision are instrumental to the success of the Group. He is currently practicing at the Institute for Spine and Scoliosis. He served as Chief of Staff and Medical Director of Spinal Cord Injury Unit at Shriners Hospital for Children in Philadelphia while serving as Professor of Orthopedic Surgery at Temple University School of Medicine. He completed his orthopedic training at Temple University, Philadelphia, with fellowship training at Alfred I. duPont Institute in Delaware. He was the President of the Scoliosis Research Society in 2005. His expertise and passion is in caring for children with pediatric spinal conditions. He can be reached at 609-912-1500 or by email at [rbetz@spineandscoliosis.com](mailto:rbetz@spineandscoliosis.com).



**Ron El-Hawary, MD** is a member of the Board of Directors for the Children's Spine Foundation. He is currently Chief of Orthopaedics at the IWK Health Centre and is Associate Professor, Department of Surgery, Dalhousie University. He is the Vice Chair of the Royal College of Physicians and Surgeons of Canada Orthopaedic Examination Committee, Secretary of the Canadian Paediatric Orthopaedic Group, and was the Founding President of the Canadian Paediatric Spine Study Group. He has a background in Mechanical Engineering and Medical Biophysics and completed his orthopaedic training at Dalhousie University and the University of Western Ontario, with fellowship training at Texas Scottish Rite Hospital in Dallas, Texas. He can be reached at 902-470-7245 or by email at [ron.el-hawary@iwk.nshealth.ca](mailto:ron.el-hawary@iwk.nshealth.ca).



**John M. Flynn, MD** is a member of the Board of Directors for the Children's Spine Foundation. He is the Associate Chief of Orthopaedic Surgery at The Children's Hospital of Philadelphia and serves as Professor of Orthopaedic Surgery at the University of Pennsylvania School of Medicine. He completed his orthopaedic training at Harvard University and the Children's Hospital of Boston, with fellowship training at Alfred I. duPont Institute in Delaware. He is the course director of the International Pediatric Orthopaedic Symposium, Chair for the Research Grants Committee for the Scoliosis Research Society and President of the Pediatric Orthopaedic Society of North America. He can be reached by email at [flynnj@email.chop.edu](mailto:flynnj@email.chop.edu).

# BOARD OF DIRECTORS

**Steve Schwartz** is a member of the Board of Directors for the Children's Spine Foundation. As President of GDS Consulting Services, LLC., he specializes in the areas of professional medical education, marketing, and medical humanitarian initiatives. He has 32 years of experience in the medical device marketplace where he held many senior management positions, including executive management of sales; executive management of professional education; and liaison with the AO Foundation (a worldwide non-profit medical research and education organization). Mr. Schwartz has worked closely with many professional societies relating to Orthopaedics, Spine, and Craniomaxillofacial surgery; and currently serves on the Boards of several non-profit organizations.



**John T. Smith, MD** is a founding member of the Children's Spine Foundation and the President of the Board of Directors. He was integral in establishing the Children's Spine Foundation and is an active participant in both retrospective and prospective studies. He is currently the Chief of Scoliosis Service and Chairman of the Division of Pediatric Orthopaedics at Primary Children's Medical Center in Salt Lake City, while serving as Professor of Orthopaedics at the University of Utah. He is also the recipient of the Mary Scowcroft Peery Presidential Endowed Chair in Orthopaedics. He completed his orthopedic training at the University of Utah and fellowship at the Scottish Rite Hospital. He has served as Chairman of several committees for POSNA and the SRS. He can be reached at 801-662-5600 or by email at [john.smith@hsc.utah.edu](mailto:john.smith@hsc.utah.edu).



**Michael G. Vitale, MD, MPH** is a member of the Board of Directors for the Children's Spine Foundation. He is currently the Chief of the Pediatric Spine Service at the Morgan Stanley Children's Hospital of New York, while serving as the Ana Lucia Professor of Clinical Orthopaedic Surgery at Columbia University College of Physicians and Surgeons. He completed his orthopedic training at the Columbia University College of Physicians and Surgeons where he also earned a Master's degree in Public Health, with fellowship training at the Children's Hospital Los Angeles. He holds leadership roles in multiple societies including co-chairing the International Pediatric Orthopaedic Symposium, and leads advocacy efforts with the FDA to improve access to pediatric devices. He can be reached at 646-831-6689 or by email at [mgv166@gmail.com](mailto:mgv166@gmail.com).



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**we**

**are**

**YOU**



# Make a Difference

The Children's Spine Foundation has a focused mission: to help children with spine problems live longer, better lives. Attaining this goal is only possible with your help. Your donation helps fund lifesaving research and provides information and support to patients throughout their journey.

## Hanna did...

Hanna Muzquiz is 11 years old and a patient of Dr. John Smith's in Salt Lake City, UT. Hanna took it upon herself to raise money for the Foundation. She first had a lemonade stand and then sold watermelons! We are so thankful for Hanna's support.



## You can too!

Your donation can help fund leading research, provide professional and public education, and support families in need.

### Online

Your secure online tax-deductible donation can be made through our website at:

[www.childrensspinefoundation.org/help.htm](http://www.childrensspinefoundation.org/help.htm)

### By Mail

Donations can be mailed in the form of check or money order, made out to "Chest Wall and Spine Deformity Research Foundation"\*, to:

Children's Spine Foundation  
P.O. Box 397  
Valley Forge, PA 19481

*\* While our name change is still in process, please ensure all donations are made payable to the former foundation name.*



## The Generosity of One Person

Mr. Hansjörg Wyss is a proven innovator and philanthropist who believes in results-focused initiatives that profoundly impact areas ranging from medicine and education to conflict resolution and land conservation. His generosity creates partnerships and establishes strategies to expand the potential of human kind. As a result, he has protected millions of acres of land, helped researchers apply groundbreaking technology, and directly improved the lives of those struggling with economic opportunity and conflict resolution.

His support of the Children's Spine Foundation profoundly impacted all aspects of our Foundation and reinforced our ability to help children with complex spine deformity live longer, better lives. His support is the reason we are able to directly support families dealing with complicated medical decisions.





# CHILDREN'S SPINE FOUNDATION

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