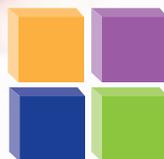




Research for Children  
2012 Annual Report



Chest Wall & Spine Deformity  
Research Foundation



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## MESSAGE FROM THE BOARD OF DIRECTORS

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*The Chest Wall and Spine Deformity Study Group is a community dedicated to improving the quality of care and the outcome of treatment for patients and families dealing with chest wall and spine deformities. This report details our successes in 2012 and our hopes for the future.*

*In 2012, we focused on strengthening our community, our research, and our outreach. We partnered with leaders in the pediatric community to produce quality research. Building upon this research, our members were awarded multiple external research grants. This perseverance and commitment to our mission ultimately enables clinicians and families to enjoy better outcomes.*

*In the coming year, we plan to expand our reach past research and education by providing access to experienced medical care to families in need. Grants will be available through the Research Foundation and will provide for travel and housing.*

*Thank you for your continued support. Together we can build upon our success in 2012 and improve the lives of many more children in years to come.*

**Randal R. Betz**  
**John M. Flynn**  
**John T. Smith**  
**Michael G. Vitale**

Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has.

Margaret Mead



# MISSION

To help children  
with spine problems  
live longer, better lives

# What Our Donors Made Possible

## 10 Noteworthy Achievements in 2012

**1** Four years ago, Dr. Jack Flynn kicked off a prospective, multicenter study to evaluate the use of rib distraction devices for preventing further progression of the Cobb angle, allowing for spinal growth and improving pulmonary function in the treatment of children with progressive scoliosis without rib abnormalities. Today, there are 72 patients enrolled.

**2** A research subgroup was formed, led by Drs. Ajeya Joshi and John Asghar, to answer the question: what happens at the end of growth surgery? This resulted in a key presentation at IMAST in Istanbul, Turkey: VEPTR Graduates: Definitive Fusion of Patients Treated with VEPTR at an Early Age.

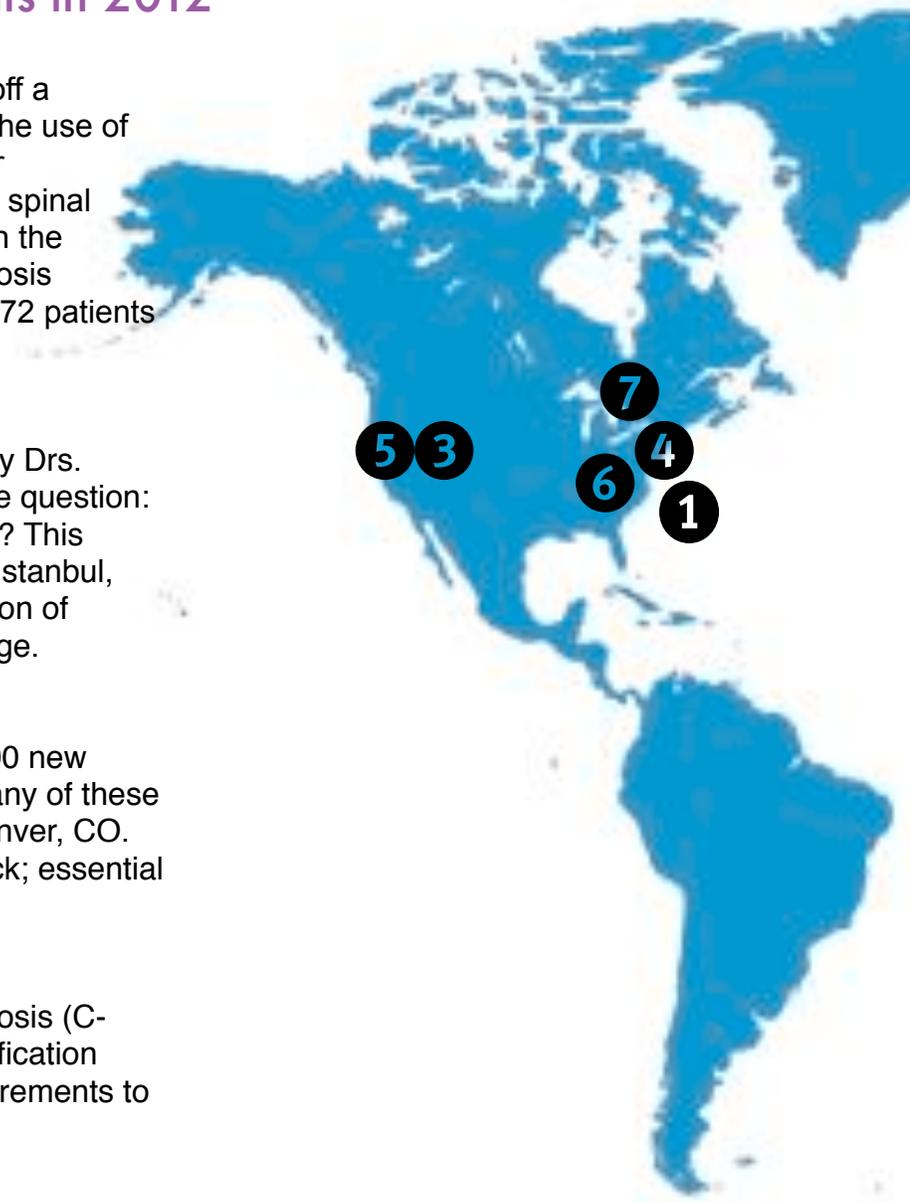
**3** The CWSD Registry enrolled almost 400 new patients in 2012 from 23 different sites. Many of these patients came from Dr. Sumeet Garg in Denver, CO. New patients are an important building block; essential for our continued research success.

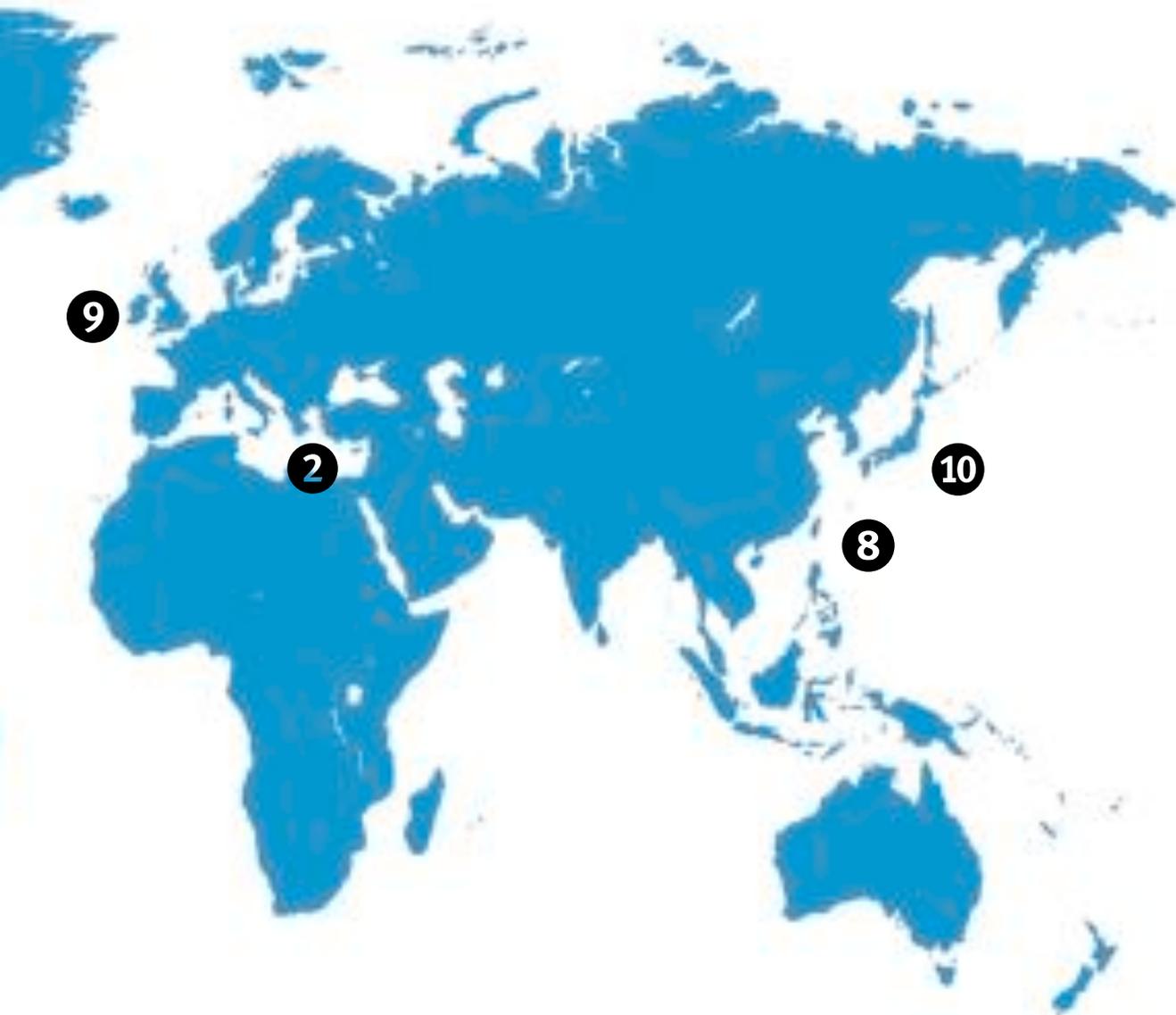
**4** The Classification for Early Onset Scoliosis (C-EOS) was introduced this year. This classification combines etiology and radiographic measurements to predict outcomes.

**5** A second classification was also introduced this year. The Complications Classification allows for meaningful comparisons between growth-sparing techniques and strategies.

**6** A major goal for the study group is to improve the quality of life of patients with early onset scoliosis (EOS). To this end, Dr. Michael Vitale pioneered a questionnaire to determine how treatments, whether surgical or non-operative, affect a child's quality of life. The EOSQ, as it is referred to, is now collected as part of our registry. To date, over 400 responses have been collected.

**7** The CWSDRF partnered with Dr. Jean Ouellet from Montreal, Quebec on an international, multicenter study looking at a new, non-fusion technology in children with complex deformity.





**8** Dr. Frank Feng, from Taiwan, attended the Study Group's Annual Research Meeting. This two-day event prioritizes research for the coming year and involves thoughtleaders in the field of pediatric orthopedics.

**9** Over 30 experts in pediatric orthopedics convened in Dublin, Ireland to collaborate on research priorities in early onset scoliosis. This was the first combined meeting of the Chest Wall and Spine Deformity Study Group and the Growing Spine Study Group, bringing together the leaders in the field.

**10** Board Member Dr. John Smith visited Dr. Noriaki Kawakami in Nagoya, Japan. There he presented his research on early onset scoliosis to 100 Japanese clinicians. He also attended the Japanese Scoliosis Society as an invited guest speaker.



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## EXECUTIVE COMMITTEE PROFILES

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**Randal R. Betz, MD** is a founding member of the Chest Wall and Spine Deformity Study Group and a current member of the Board of Directors. His leadership and vision are instrumental to the success of the Group. He is currently 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:

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**Robert M. Campbell, MD** is a founding member of the Chest Wall and Spine Deformity Study Group and a strategic advisor to the Board of Directors. Together with Melvin Smith, MD, he is the inventor of the VEPTR™ device and performed the majority of the initial surgeries. He is the Director of the Center for Thoracic Insufficiency Syndrome at The Children's Hospital of Philadelphia. He completed his orthopedic training at Fitzsimons Army Medical Center in Denver, Colorado, with fellowship training at Alfred I. duPont Institute in Delaware. He works closely with the FDA and was recently honored by the House of Representatives for providing children with lifesaving medical care.



**John T. Smith, MD** is a founding member of the Chest Wall and Spine Deformity Study Group and a member of the Board of Directors. He was integral in establishing the Chest Wall and Spine Deformity Research Foundation and is an active participant in both retrospective and prospective studies. He is currently the Director of the Pediatric Scoliosis Clinic and Chairman of the Division of Pediatric Orthopaedics at Primary Children's Medical Center in Salt Lake City, while serving as Professor of Orthopaedics and Pediatrics at the University of Utah. He completed his orthopedic training at the University of Utah and fellowship at the Scottish Rite Hospital in Atlanta. He has served as Chairman of several committees for POSNA and the SRS. He can be reached at:

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## EXECUTIVE COMMITTEE PROFILES

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**John M. Flynn, MD** is a member of the Board of Directors for the Chest Wall and Spine Deformity Research Foundation. He acts as a strategic advisor and currently leads one of the Group's major prospective studies focused on early onset scoliosis. 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-Elect of the Pediatric Orthopaedic Society of North America.



**Michael G. Vitale, MD, MPH** is a member of the Board of Directors for the Chest Wall and Spine Deformity Study Group. He guides the Group's research direction and is an active participant in both retrospective and prospective studies. He is currently the Chief of the Pediatric Spine Service at the New York - Presbyterian Morgan Stanley Children's Hospital, 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. He then completed his fellowship at the Children's Hospital Los Angeles. He holds leadership roles in the American Academy of Pediatrics, the Pediatric Orthopaedic Society of North America, the International Pediatric Orthopaedic Symposium, and the Scoliosis Research Society, and leads advocacy efforts with those organizations working with the FDA to remove obstacles to innovation for kids who need specific medical devices not currently available. He can be reached at:

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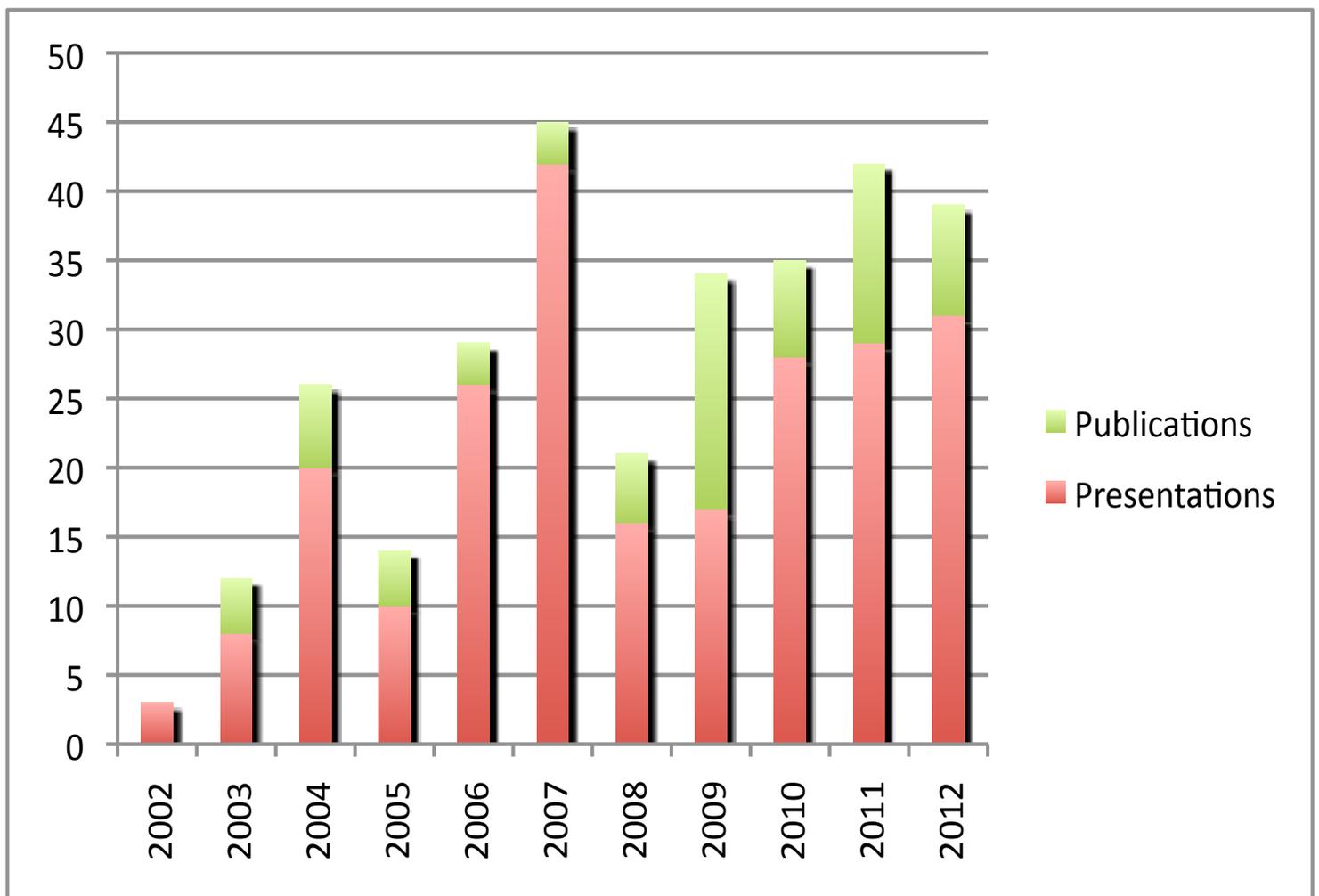
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# ACADEMIC PRODUCTIVITY

Study Group productivity includes both clinical and basic research. Clinical research articles describe the latest evidence on the treatment, diagnosis, and/or prognosis of musculoskeletal disorders. They may also include reports on complications and outcomes. Basic research studies explore the mechanisms of musculoskeletal disorders and/or their treatment. They may also include the use of new technology for analysis of etiology. The following publications and presentations represent the work of Study Group participants.





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# Key Presentations

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## **The Early-Onset Scoliosis Questionnaire (EOSQ) Reflects Improvement in Quality of Life After Growing Surgery**

Daren J McCalla, Hiroko Matsumoto, MA, Kumar Nair, Brendan A Williams, BA, Jacqueline Corona, MD, Behrooz A Akbarnia, MD, John Emans, MD, David L Skaggs, MD, John T Smith, MD, Benjamin D Roye, MD, MPH, David P Roye, MD, Michael G Vitale, MD, MPH  
Scoliosis Research Society, Dublin, Ireland

Summary: Traditional measures of outcome following treatment for Early Onset Scoliosis (EOS), such as correction of Cobb angle, fail to capture the patient and caregiver experience. The Early Onset Scoliosis Questionnaire (EOSQ) has been developed to reflect quality of life (QOL) and caregiver impact in children with EOS before and after treatment interventions. The purpose of this study is to validate the EOSQ by examining the responsiveness of this measure to surgical interventions, and to establish normative reference scores. The study validated that the measure shows differences in QOL before and after surgery and appears to be an appropriate measure of outcome in comparing treatment options in this group of patients. It is applicable to children aged 0-18 years. Psychometrics, including few ceiling or floor effects, appear excellent.

## **An Improved Rabbit Model for Thoracic Insufficiency Syndrome**

Brian D Snyder, MD, PhD, John C. Olson, MS, Michael A .Pitts-Kiefer, Michael P. Glotzbecker, MD  
Pediatric Orthopedic Society of North America, Denver, Colorado

Summary: The modified rabbit model for TIS reproduces the post-natal pulmonary hypoplasia, scoliosis, and chest wall deformity observed clinically. This model appears to be sufficient to investigate the pathophysiology of TIS. Explicit evidence is shown that the extent of scoliosis and chest wall deformity existent in a young, growing child will predict the severity of TIS in the untreated adult.

## **VEPTR Graduates: Definitive Fusion of Patients Treated with VEPTR at an Early Age**

Jahangir Asghar, Ajeya Joshi, Joshua Pahys, Harry Shufflebarger, Timothy Uschold, Tricia St. Hilaire, Sumeet Garg, Randal Betz, Charles d'Amato, Michael Vitale, John Flynn, John Smith, Amer Samdani  
International Meeting on Advanced Spine Techniques, Istanbul, Turkey

Summary: No previous studies have evaluated the surgical outcomes for patients undergoing definitive fusion after VEPTR placement. We reviewed 33 patients and report autofusion occurring in half of these patients, with a subsequent coronal Cobb correction of 39.8%. Our study shows definitive fusion post VEPTR is a feasible and effective treatment. However, given the complexities associated with this cohort, a strong need exists for prospective analysis of the maturing VEPTR population to optimize outcomes.

Reaching our mission is not possible without the help of the community supporting us.

This year we have had two significant commitments. The first is from a longstanding partner and supporter of our cause, DePuy Synthes. The second is from a generous individual, Mr. Hansjörg Wyss. Mr. Wyss has pledged his long-term support in the areas of education, research, and patient care. His commitment allows us to continue to work towards our mission and directly impact the patients we treat.

Those who donate are able to experience the satisfaction of giving and making an immediate impact through gifts large and small. Some give in honor of another's success or in memory of someone lost. Others, making larger charitable investments, focus their giving on a particular aspect of the mission, whether it be research or patient care.

*The greatness of a community is most accurately measured by the compassionate actions of its members, a heart of grace and a soul generated by love.*

Coretta Scott King



The CWSDRF is a small community with a very big mission.

With minimal overhead and 3 full-time employees,  
we have worked together to study over 1600 patients including 225 diagnoses.  
We have published 70 papers and presented over 180 scientific studies at expert meetings.



Sarah Mumford, MBA  
Administrative Director



Tricia St. Hilaire, MPH  
Executive Director



Tara Flynn  
Data Analyst

With your help, we can continue to make life better for our existing and future patients.



## Our Vision

*"As part of the Study Group, I want to be able to guide families making difficult treatment decisions for their children with better quality information about the risks and benefits of various treatment options. Although our knowledge base is growing, much of our discussions now simply describe what we think is the best option, but acknowledging we don't have data to support those beliefs. I am certain this can be frustrating for parents to hear.*

*Most parents are excited to participate in the research efforts of the CWSD because they are experiencing the uncertainty of how to take care of their children and want to help other parents have an easier time in the future. I feel a sense of partnership and pride with both my participating families and my colleagues in the study group to gain more information about how to best care for children with chest wall and spine deformities."*

Sumeet Garg, MD  
Core Member



*"Early onset scoliosis is a challenging condition to treat. Our current treatment options are innovative, but not yet perfect. Our group is striving towards the optimal treatment of this condition... a treatment that is effective at controlling the progression of scoliosis and maintaining lung development. Multicenter research gives our group the strength in numbers that allows us to achieve these goals and to help these young children."*



Ron El-Hawary, MD  
Core Member

The CWSD Research Foundation is a nonprofit organization that relies on the generosity of individual, foundation, and corporate contributions to advance its mission.



## Why CWSDRF

Children with spine and chest wall disorders are considered an "orphan population", meaning limited to a small percentage of the population. Because of this, research is challenging, yet necessary for the evolution of treatment.

The CWSDRF funds research based on medical need without regard to the size of the population.

## Make a Difference

**Reaching our goal is only possible with your help.**

The gift you make today will support research that will make a difference to children with spine and chest wall problems. Your secure, online tax-deductible donation to the Chest Wall and Spine Deformity Research Foundation (CWSDRF) helps fund lifesaving research and provides information and support to patients throughout their journey.

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