



CHILDREN'S
SPINE
FOUNDATION®

2014

~~ANNUAL
REPORT~~

Our story

A MESSAGE FROM OUR PRESIDENT



I first met Presley and her family when she was 16 months old. After visiting many other specialists for her complex spine deformity, they came into my office as a last resort. Presley had been through countless respiratory sicknesses and needed help. Because of my involvement with the Children's Spine Foundation, I was able to review our database of children living with rare, yet severe spinal deformity to find other children similar to Presley. I was able to review research results on cases like hers. Because of the Children's Spine Foundation, I was able to offer Presley and her family hope.

The Children's Spine Foundation is committed to improving access to comprehensive care for our most complex patients; to expanding our study of treatments to encompass those being used without strong scientific support; and to the education of the clinical community to benefit all children living with complex spine deformity.

This report is more than just an annual financial update. It is proof that we are making a difference to children like Presley. It is about the 2400 children and their families that we help treat. It is about all the children we have yet to meet; about planning for their future and ours; and about how you can join us to support our cause.

This is our story.

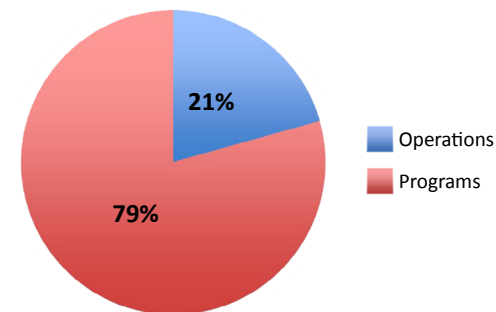
John Smith, MD
Chairman, Children's Spine Foundation



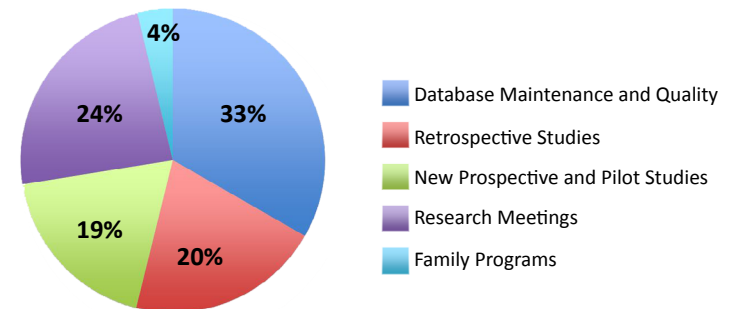
"Non-profits that spend 25% or less of their budgets on fundraising, management, and administration are regarded as highly efficient and earn an A grade."

- CharityWatch

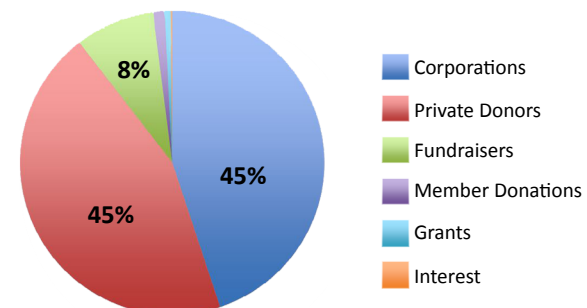
ALLOCATION OF FUNDS



PROGRAM ALLOCATION



FUNDING SOURCES





In 2014, the Children's Spine Foundation spent over \$400,000 to support **medical access**, **research**, and **education** in the area of early onset scoliosis.

Through our support of active research projects, we are working to answer the following questions for patients with early onset scoliosis:

- How can we improve the quality of life?
- When should patients be treated with a cast to achieve the best clinical result?
- What are the best operative and non-operative treatment options?
- What are the long-term outcomes?
- How does thoracic deformity impact respiratory function during growth?
- Can hemoglobin be used as an indicator for pulmonary function?

Answers to these questions are used by clinicians around the world to improve the treatment of early onset scoliosis.



Our Database

In 2014, 457 new patients were enrolled into the Children's Spine Foundation Early Onset Scoliosis database. There are now 2,555 patients that are being followed at 25 participating medical centers, making it the largest database of it's kind in the world. Over 10,000 patient visits and progress reports have been entered. This data is used by researchers around the globe to improve the life of children dealing with early onset scoliosis.

Family Support

Our Families In-Need Program was launched in 2013. This program was created specifically to help 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. If you would like more information, please contact us at info@childrensspinefoundation.org.

Research Grants

A large part of our mission is to dramatically improve the global care of young children dealing with life-threatening spinal deformity through groundbreaking research. We have produced over **90 clinical research publications** which provide the latest evidence on the treatment, diagnosis, and prognosis of early onset scoliosis. We also support **basic science research** which explores the mechanisms for deformities and their treatment. Lastly, we study **new treatments and technology** to produce evidence to support best possible outcomes for children with complex spine deformity.



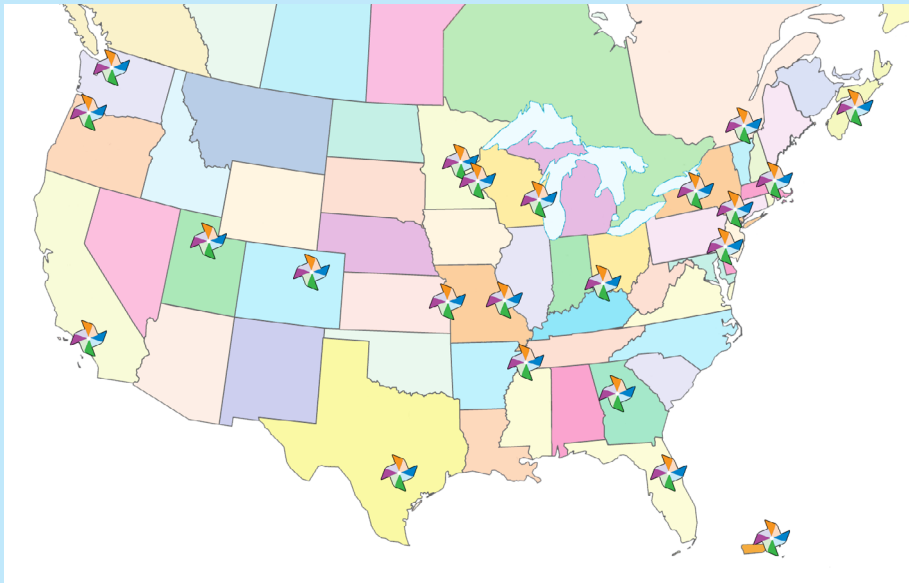
Our Story

Braydon was born with severe scoliosis and fused ribs. Without treatment, his condition would have impacted his ability to walk and breathe. For children like Braydon, early onset scoliosis takes a drastic toll on childhood activities and health. It is usually accompanied by other medical issues such as diminished lung function, muscle weakness, or benign or malignant tumors. It is found in children under the age of 10 who have abnormal spinal curvature. Sadly, children with early onset scoliosis have a 10% chance of dying before their 10th birthday.



Through the Children's Spine Foundation, researchers from our 25 sites are dedicated to changing this. Each day children like Braydon undergo treatment with the hope that our efforts make their story brighter than it has been in the past.

Research Sites in North America



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 and families throughout their journey.

Become a part of our story today.

2014 Key Donors

Mr. Hansjörg Wyss' multi-year gift has profoundly impacted all aspects of our Foundation and allows us to work tirelessly towards our mission.

DePuy Synthes Spine, a strong supporter over many years, generously supported various research projects.

About Us

Over the past ten years, the Children's Spine Foundation has partnered with researchers from leading pediatric medical institutions to better understand spine deformity in young children and how to treat it. Today our research has improved the lives of so many children, making their story brighter than it has been in the past. However, there remain many unanswered questions. Our Foundation and our clinical partners are dedicated to finding answers. The Children's Spine Foundation is a 501(c)(3) non-profit foundation which relies solely on donations to pursue our mission.

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