

Inspire. Educate. Act.



Be inspired.

Spread awareness.

Make a difference.

Help us beat SMA.

**LIVE RHYSSTRONG
FOUNDATION**

Phone: 415 606.7424

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www.liverhysstrong.org

 facebook.com/liverhysstrong

 [LiveRhysStrong](https://www.instagram.com/LiveRhysStrong)

 [LiveRhysStrong](https://www.twitter.com/LiveRhysStrong)



**Live RhysStrong
Foundation**

Public Charity benefitting
the SMA community.



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Live RhysStrong Foundation



Rhys Anthony Santiago
7/3/13 – 8/26/13

About Us

The Live RhysStrong Foundation was founded in memory of little Rhys Anthony Santiago, who was diagnosed with Spinal Muscular Atrophy (SMA) at the young age of 5 weeks. He grew his angel wings on August 26, 2013, the day the foundation was started. In his 55 days he inspired others to help in any way they can, and his inspiration continues to burn bright.

Our goal is to increase visibility of this disease, help raise funds for research and help affected families.

We are a 100% volunteer-supported organization currently entirely funded by donations.

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Raising Awareness

Awareness is everything.

It starts with awareness. Many people have never heard of this devastating disease. What is SMA?

- It is the #1 genetic killer of infants
- 1 in 50 people are carriers of SMA
- 1 in 8,000 people are affected
- Most people don't know their carrier status
- SMA currently has no treatment or cure
- There are 4 types of SMA
- Type 1 is the most severe

Early detection is key. Know your carrier status. It's as easy as asking your doctor for a carrier screening test.

We will be holding various events throughout the year. For more information on how you can help Live RhysStrong and the SMA community, please visit www.liverhysstrong.org, call us at 415 606.7424 or e-mail us at info@liverhysstrong.org.

Raising Funds for Research

It's all about hope.

SMA affects the muscles used for breathing, swallowing, sitting, standing and crawling. When muscles do not receive a particular protein, in this case the Survival Motor Neuron (SMN) protein, they atrophy and motor neurons die. The National Institute for Health has categorized SMA as a rare disease, affecting less than 200,000 people. Most of today's treatments were originally funded by family organizations. Every penny raised helps further this cause.

A Community in Need

It takes a village.

They say it takes a village to care for a child affected with SMA. Care is also very expensive and hard to find. And when it is found, transportation and mobility are difficult to obtain. Families are also often faced with dealing with the cost of expensive medical equipment and investing their time for proper training. We work to help affected families provide the care and opportunities their children deserve.



SMA affects one in 6,000 – 10,000 people.