

**From: Families of SMA  
Libertyville, IL**

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### **300 Million Americans = 7.5 Million Carriers of Spinal Muscular Atrophy**

**Libertyville, IL October 17, 2006** — With the birth of the 300 Millionth person in the United States comes a more sobering statistic... 7.5 Million Americans are carriers of the disease Spinal Muscular Atrophy (SMA).

SMA is the leading genetic killer of children under the age of two. SMA is an often fatal disease that destroys the nerves controlling voluntary muscle movement. 1/2 of children diagnosed with the most severe form will not reach their second birthday. There is no cure for SMA, but new understanding has led to breakthroughs in potential treatments, FSMA is funding:

#### **Project Cure SMA**

Project Cure SMA is a multi-center clinical trials network. Currently the network is performing a phase II clinical trial to further evaluate a combined regimen of valproic acid and carnitine in children with SMA. This trial was reviewed by the FDA and is fully funded by Families of SMA.

#### **Drug Discovery**

FSMA is supporting 2 different drug discovery programs for SMA -- one at Paratek Pharmaceuticals and one at deCODE genetics. Our program at deCODE is one of the most aggressive drug discovery programs ever undertaken by a non-profit organization with over \$10 million of funding already committed. If these programs continue on schedule there is hope that FSMA will be applying to the FDA to begin phase I testing in 2007.

#### **Additional Research**

In addition, FSMA is currently funding 24 basic research grants in order to accelerate a cure for SMA.

#### **About Families of SMA**

Since its inception in 1984, Families of SMA has funded more than \$25 million in research. In addition, FSMA has provided more than \$3 million dollars in patient services. FSMA is a volunteer-driven nonprofit organization based in Libertyville, IL; founded by parents of children suffering from SMA. FSMA is dedicated to eradicating SMA by promoting and supporting research, helping families cope through informational programs and support, and educating the public and the medical community about SMA. The organization has more than 24 chapters worldwide and more than 5,500 member families.

Please visit the website [www.curesma.com](http://www.curesma.com) for more information on this disease and the organization.

*For more information or to arrange an interview contact: Lenna Scott 847-975-4171*