

May 22, 2009

We are very pleased to announce that legislation to enhance federal support for Spinal Muscular Atrophy (SMA) research, S. 1158, the **“SMA Treatment Acceleration Act of 2009”**, has been introduced in the Senate by Senator Debbie Stabenow (D-MI) and Senator Johnny Isakson (R-GA). Congressman Patrick Kennedy (D-RI) and Congressman Eric Cantor (R-VA) introduced companion legislation, H.R. 2149, in the House on April 28, 2009. On behalf of our organizations and the families affected by this deadly disease, we want to express our gratitude and thanks to Senators Stabenow and Isakson and Congressmen Kennedy and Cantor for their leadership.

This legislation builds upon the success of the SMA Treatment Acceleration Act introduced in the 110<sup>th</sup> Congress, which garnered 21 cosponsors in the Senate and 85 cosponsors in the House. The new version of the legislation has been modified slightly to ensure resources for SMA clinical efforts and infrastructure are maximized.

SMA is the number one genetic killer of children under the age of two. It is an inherited disease that destroys the nerves controlling muscle movement, which affects crawling, walking, head and neck control, swallowing, and breathing. Approximately one in 40 people, or approximately 7.5 million Americans, carries the gene mutation that causes SMA. Each child of two carriers of the mutant gene has a one in four chance of being affected by SMA.

Among more than 600 neurological disorders, SMA has been singled out by the National Institutes of Health (NIH) as one of the diseases closest to treatment based on scientists' advanced genetic understanding of the disease and a strong collaboration between families, federal agencies, and patient advocacy groups. Researchers have identified the gene responsible for SMA, as well as a disease modifying “back-up” gene that has opened the door to promising new treatment pathways. This research is providing groundbreaking data for SMA and other disorders, including the muscular dystrophies, Lou Gehrig’s disease, Friedreich’s Ataxia, Fragile X syndrome, and Huntington’s disease.

In order to build on the progress being made by investigators and bring treatments to children affected by SMA, a broad coalition of organizations, including Families of SMA, FightSMA, the Muscular Dystrophy Association (MDA) and the SMA Foundation, has united behind the SMA Treatment Acceleration Act of 2009, legislation aimed primarily at supporting a national clinical trials network for SMA.

Specifically, the **“SMA Treatment Acceleration Act of 2009”** provides for the following:

- Federal support for a national clinical trials network for SMA;
- Federal support to enhance the SMA patient registry and for expanded research on the epidemiology of SMA;
- Establishes an Interagency SMA Research Coordinating Committee to include federal agencies including NIH, SMA researchers, and SMA families, to coordinate government activities relating to SMA, develop a comprehensive strategy for improving and expanding SMA research, make recommendations to strengthen collaborative research across multiple institutes at NIH, and identify barriers to the development of drugs for treating SMA; and
- Provides for the Secretary of HHS to establish a program to provide information and education on SMA to health professionals and the general public.

Our organizations are issuing a “Nationwide Call to Action” for all SMA families, researchers, and friends, to help engage every Member of Congress in support of this bill and the great efforts of Senators Stabenow and Isakson and Congressmen Kennedy and Cantor.

Kenneth Hobby  
Families of SMA

Martha Slay  
FightSMA

Annie Kennedy  
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NOTE: For more information on the **“The SMA Treatment Acceleration Act”** please contact any one of our Government Affairs staff:

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