



SMA:

Treatment within Reach, Finally

Spinal Muscular Atrophy (SMA) is the leading genetic killer of infants and toddlers, and even in less severe cases, causes tremendous suffering and eventual death. It is untreatable, incurable, and fatal. But today is a brighter day for an estimated 25,000 Americans who suffer from SMA, and the seven million potential parents carrying the gene that can doom their children.

Thanks to spectacular scientific innovations over the past seven years, and the persistence of a select group of lawmakers, there is hope.

Researchers at the National Institute of Neurological Disorders and Stroke (NINDS) and the National Institutes of Health (NIH) recently designated SMA as a model disease for translational research funding – research focused on translating basic scientific research into actual treatments and drugs for SMA patients.

Translational research is critical to the development of a treatment not only for SMA, but also for other similar diseases.

Many members of Congress have joined Senator Jon Corzine (D-New

Jersey), and Representatives Randy "Duke" Cunningham (R-California) and Susan Davis (D-California), to strongly urge NIH and NINDS to move expeditiously to fully fund and implement the translational research program to accelerate a treatment or cure for SMA. A special thanks also to the Senate Labor/HHS/Education Appropriations Subcommittee, led by Senators Arlen Specter (R-Pennsylvania) and Tom Harkin (D-Iowa), for recognizing the needs of children with SMA and encouraging NIH to move forward expeditiously on SMA translational research in the FY03 Committee Report.

Tens of thousands of families who have been devastated by this terrible disease, and millions of parents who carry this gene, are grateful for their support. Their efforts could mean the difference between life and death for thousands of children, and will help give 25,000 Americans the chance at life they deserve.

To view the full Congressional letters to NIH in support of SMA research, log on to: www.smafoundation.org/government.

SMA Families Thank Our “Champions of Children” in the United States Congress

U.S. Senate

Daniel Akaka
George Allen
Evan Bayh
Jeff Bingaman
Barbara Boxer
John Breaux
Jim Bunning
Ben Nighthorse Campbell
Lincoln Chafee
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