



Muscular Dystrophy Association
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April 10, 2008

Representative Patrick Kennedy
407 Cannon House Office Building
Washington, D.C. 20515-3901

Dear Representative Kennedy:

As President and CEO of the world's leading SMA research and services organization, I'd like to thank you for supporting the thousands of American children and adults living with Spinal Muscular Atrophy through your sponsorship of H.R. 3334, the SMA Treatment Acceleration Act.

SMA is a devastating motor neuron disorder that occurs in an estimated one in every 6,000 births and is considered to be the number-one fatal genetic disease in children under age 2. Forms of SMA strike infants and toddlers and progressively inhibit their ability to walk, move, breathe, and swallow. This is a cruel disease that does not discriminate; approximately 7.5 million Americans are thought to carry the gene that causes SMA.

Since MDA's inception in 1950, our commitment to the SMA community has been unwavering. We're delighted that our decades of contributions to research funding and clinical efforts have yielded significant advances in the scientific understanding of, and potential treatments for, this insidious disease. Now, more than ever, it's critical that a national clinical trials network be established for SMA, as well as a forum for collaboration between appropriate federal agencies.

As an organization founded on the belief that *'there is no such thing as an incurable disease, only diseases for which cures have yet to be found,'* we're hopeful that the SMA Treatment Acceleration Act will provide vital momentum to the scientific quest for effective treatments for Spinal Muscular Atrophy. If there is any way in which MDA or our National Chairman, Jerry Lewis, can help to further your effort, please contact Annie Kennedy, MDA's Vice-President of Advocacy, in our Washington, D.C.-based Advocacy office at akennedy@mdausa.org or (202) 828-8560.

Again, I thank you for your leadership and support.

Sincerely,

Gerald C. Weinberg
President & CEO

GCW/dmb

cc: Jerry Lewis
Annie Kennedy