June 11, 2008

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The Honorable Joe Knollenberg
United States House of Representatives
2349 Rayburn House Office Building
Washington, DC 20515

Dear Congressman Knollenberg:

As your constituent, I am writing to you today to ask you for your support of H.R. 3334, the "**SMA Treatment Acceleration Act**," which has been introduced by Congressman Patrick Kennedy (D-1st-RI) and Congressman Eric Cantor (R-7th-VA) in the U.S. House of Representatives. The companion bill was introduced in the Senate in early September, led by Senator Debbie Stabenow (D-MI) and Senator Johnny Isakson (R-GA). This Act will go a long way in our efforts to find a cure for Spinal Muscular Atrophy (SMA), the leading genetic killer of children under the age of two.

On August 24th, 2007 our 4 month old son was diagnosed with SMA Type 1. The doctors told us there was nothing more they could do for him and we should take him home and love him for as long as we have him. He passed away 3 months later on November 28th, 2007.

As you may know, SMA is a hereditary disorder that destroys the nerves controlling voluntary muscle movement. It is the number **one** genetic killer of children under the age of two. SMA is a relatively common "rare disorder." It is estimated that SMA occurs in about 1 in every 6,000 births. Approximately 1 in 40 individuals (7.5 million Americans) carry the gene that causes SMA, making it the second most common autosomal recessive genetic disorder. This incidence rate shows neither racial nor gender bias.

Presently, there is no known treatment for SMA, though there have been several exciting research breakthroughs over the past decade. Among more than 600 neurological disorders, SMA has been singled out by the National Institutes of Health as the disease closest to treatment based on scientists' advanced genetic understanding of the disease.

In order to support the investigators, clinicians, and families who are working to find a treatment or cure for SMA, the SMA community, including Families of SMA, the SMA Foundation, and Fight SMA, has united behind the "**SMA Treatment Acceleration Act.**" Specifically, "The SMA Treatment Acceleration Act" would provide for the following:

- Federal support for a national clinical trials network for SMA;
- Federal support to enhance the existing SMA patient registry and for expanded research on the epidemiology of SMA;
- Establishes a SMA Coordinating Committee to include federal agencies, SMA researchers, and SMA families;
- Establishes a trans-Institute research collaboration at NIH under the Director of NIH to ensure all relevant Institutes at NIH are contributing and collaborating on SMA research;
- Requires the Secretary of the U.S. Department of Health and Human Services (HHS) to study and report to Congress on ways to improve existing incentives, as well as to recommend additional incentives, necessary to promote SMA drug development among private industry;
- Lastly, the bill provides for the Secretary of HHS to establish a program to provide information and education on SMA to health professionals and the general public

We are excited about this legislation and to that end; we encourage you to sign on as a cosponsor to the "**SMA Treatment Acceleration Act.**" Congressman, if you are interested in cosponsoring, or if you have any questions, please ask members of your staff to contact Rachel Bornstein with Congressman Kennedy at 202-225-4911; or Lindsay Shore with Congressman Cantor at 202-225-2815.

With your help, there is real hope for finding a cure for SMA. Thank you for your help!

Sincerely,

Tony Deddeh
5755 King James Lane
Waterford, MI 48327
tdeddeh@earthlink.net