

## Local family to meet with Congressional Representatives at National Spinal Muscular Atrophy Research

*Contributed Report*

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An area family is traveling to the nation's capital to advance the fight against the deadly disease spinal muscular atrophy (SMA). Wayne & Carice Smith of Mechanicsville will be meeting with Congressman Eric Cantor and Senators, John Warner and Jim Webb while attending the twelfth annual FightSMA national conference, "The Good Fight."

Spinal muscular atrophy is an incurable neuromuscular disorder that kills more infants than any other genetic disease. Smith's son, Andrew Creighton, age 14 has been diagnosed with the disease. Spinal muscular atrophy affects the motor neurons of the spinal cord and brain stem, rendering them unable to communicate with muscle cells properly. It is estimated that it occurs in as many as one in 6,000 births. The National Institute of Neurological Disease and Strokes (NINDS) of the National Institutes of Health (NIH) states, however, that out of the 600 disorders it tracks, SMA is one of the closest to being cured. FightSMA is an international nonprofit organization dedicated to accelerating that cure. The Smith family and others from across the country will meet with their Senators and Representatives to urge them to support the creation of the first ever spinal muscular atrophy legislation.

The proposed SMA Treatment Acceleration Act would establish a national clinical trials network to develop treatments that are safe and effective for SMA patients

"The conference attendees are able to explain better than anyone why the fight against spinal muscular atrophy is so critical," said FightSMA President Martha Slay. "We know these very important meetings with members of Congress will help to put a face on this horrible disease."

Attendees will also have the opportunity to receive updates on research into the disease from scientists from all over the world, gain valuable and practical advice from clinicians for coping with a childhood disease on a daily basis. For more information on the conference, please visit the FightSMA conference web page, at [http://www.fightsma.org/index.php?annual\\_meeting\\_2007](http://www.fightsma.org/index.php?annual_meeting_2007)



Congressman Eric Cantor with Andrew Creighton of Mechanicsville.

### About FightSMA

Headquartered in Richmond, Virginia, FightSMA (also known as Andrew's Buddies) is an international nonprofit group dedicated to accelerating research for a treatment or a cure for spinal muscular atrophy (SMA), a neuromuscular disorder that kills more babies than any other genetic disease.

For more information on spinal muscular atrophy and FightSMA, please visit <http://www.fightsma.org>.

The latest SMA news and research information is available at the Spinal Muscular Atrophy Blog, at <http://www.fightsma/blog>.