



## **SMA COALITION UPDATE**

### **SMA Coalition Day on Capitol Hill Recap**

#### **Greetings to all of our SMA Coalition Members and our Helping Hands!**

Last Thursday, April 27<sup>th</sup> marked our 4<sup>th</sup> Annual SMA Coalition Day on Capitol Hill!

We are happy to report that, once again, the SMA Coalition families and friends who participated had a very successful day on Capitol Hill!

SMA families and friends from across the country met with over 60 Senators, Congressmen and Congresswomen and key health staff to raise awareness about SMA and to ask for their support in increasing federal resources dedicated to developing treatments and a cure for SMA.

We were very pleased to have such a large turn out of family and friends this year and were happy to welcome many new families to the SMA Coalition Day on the Hill!

These meetings on Capitol Hill each year are critical to raising and maintaining awareness of SMA among Members of Congress and we are very thankful to all the families and friends who made the trip to Washington, DC this year for this very important day!

Below are just some of the pictures and some of the feedback from families who participated in the SMA Coalition Day on the Hill that we thought you would enjoy. If you would like to know more about our specific agenda for our meetings with Members of Congress, or if you would like to reach out to your Member of Congress back in their district, please let us know and we would be happy to assist you in making outreach to your Members to educate them on SMA.

## Pictures from the 2006 SMA Coalition Day on Capitol Hill



Patrick (SMA Type II) and Maureen Higgins from Westfield New Jersey visiting with Congressman Mike Ferguson (*left*)

Congressman Kingston showing William (SMA Type II), Tonya and Ben Mason, from McDonough, Georgia, his model plane (*right*)



Anne Meguiar from Richmond Hill, Georgia updating Congressman Kingston on our ongoing efforts to find treatments and a cure for SMA (*left*)



Cheryl Augustino from Powhatan, Virginia visits with her Congressman Randy Forbes (*left*)

Congresswoman Myrick takes time out of her busy day to meet with John and Holly Bolton of Huntersville, North Carolina (*right*)



## **More Feedback from SMA Families from the Halls of Capitol Hill**

*“Very positive, I felt like he will follow through on our requests and continue to support the SMA Coalition.”*

*“Excellent reception, response. Met the Congressman...did quick photo op. His office, staff could not have been kinder to us”*

*“It was a positive meeting and he was very receptive to everything we asked and sympathetic to our cause”*

*“Played catch up. 3<sup>rd</sup> time to see him. He is glad to see the progress we are making and will keep pushing for us”*

*“The staff did not know anything about SMA but was willing to listen and learn”*

*“We introduced ourselves. She had obviously done some research on SMA and was certainly aware of why we were there”*

*“Very positive. Remembered us from last year and seemed excited to hear of our progress with Dr. Alexander at NICHD”*

*“Congresswoman was extremely receptive to our requests. She commended us for coming back and said it was wonderful that we were advocates for our children.”*

*“Good meeting, they know we are serious and that we are making progress”*

*“Excellent. A mom with a child with SMA type II walked in on our meeting. She was lobbying for another cause! It was perfect!”*

*“Very, very positive. Excited I was active member of community especially among medical and in touch with other SMA families in the area. Gave local info especially Medical state programs we access and other medical issues”*

*“Positive, she had never heard of SMA before, understood what we were asking for”.*

**GREAT WORK SMA COALITION!  
EVERY VISIT, EVERY OUTREACH TO YOUR MEMBERS OF  
CONGRESS MAKES A DIFFERENCE!**