



November 2, 2009

Dear SMA families, researchers, clinicians and friends,

Thank you again for all you have done to help increase awareness and attention towards our efforts to accelerate treatment and cure discovery for Spinal Muscular Atrophy (SMA). As we continue to promote the SMA Treatment Acceleration Act (H.R. 2149/S. 1158) in the current Congress, many important questions have been posed regarding the status of the bill, the political climate in Washington, and the need for sustained grassroots engagement. In response to these queries, we have put together a list of frequently asked questions (FAQs). Please find below answers to these FAQs.

We hope that this information clarifies the incredible progress made to date and the path forward for the SMA Treatment Acceleration Act. Your continued support for the Act is the key component of our strategy to see this legislation enacted. While we cannot make guarantees of success, we can state unequivocally that we are making excellent progress and have a strategy in place to accomplish our goal. The legislative process requires persistence and patience – please continue to remain engaged and active participants as you are integral to our success.

Thank you very much for your continued support and involvement.

Sincerely,

The SMA Government Relations Team

Spencer Perlman  
Families of SMA  
[spencer@fsma.org](mailto:spencer@fsma.org)

Caroline Gibson  
FightSMA  
[carolinegibson@fightasma.com](mailto:carolinegibson@fightasma.com)

David Miller  
MDA  
[dmiller@mdausa.org](mailto:dmiller@mdausa.org)

Laura Lay  
SMA Foundation  
[llay@swdc.com](mailto:llay@swdc.com)

NOTE: If you have additional questions about the “SMA Treatment Acceleration Act” or for more information, please feel free to contact us at any time.

### **FAQs about the SMA Community’s Progress with the SMA Treatment Acceleration Act**

#### **Q1: Where do we stand with the SMA Treatment Acceleration Act? How does our pace compare to the previous Congress?**

The SMA Treatment Acceleration Act has made good progress thus far in the 111<sup>th</sup> Congress, which runs from January 2009 – January 2011. The Act was reintroduced in the House of Representatives at the end of April and in the Senate at the end of May following months of discussion between the SMA community and the bill’s sponsors, staff for the congressional committees with jurisdiction over health care matters, and federal agency partners.

Thanks to our community’s tireless outreach over the past several months since reintroduction, the SMA Treatment Acceleration Act already has gained 57 cosponsors in the House and 15 cosponsors in the Senate, placing us well ahead of our pace in the 110<sup>th</sup> Congress. (A list of current cosponsors can be found below.) In

fact, nearly half of our cosponsors in the House have been added in the five weeks since Congress returned from its August recess, a testament to the power of our community's collective voice and the momentum we have achieved.

**Q2: Why have some Members of Congress who previously supported the Act not yet signed on to the newest version?**

It is important to understand the current political climate in Washington in order to appreciate the speed with which the Act is gaining support among lawmakers. For most of 2009, health care reform has been an all-consuming process for Members of Congress and their health care staff, largely eclipsing all other health-related measures in Congress. Thus, many of our supporters in Congress have not yet had the time to consider the changes to the bill and express their support. This does not mean that those Members will not cosponsor the legislation, but rather, that an unprecedentedly busy legislative calendar has demanded that all of their time and is focused on the health care reform at this time.

Please know that the calls, letters and e-mails from the SMA community are not being ignored by Members or their staff. In fact, our continued outreach remains integral to the success of this bill as it builds support for the legislation and will make the SMA Treatment Acceleration Act a priority for lawmakers when health care reform is complete.

**Q3: What are our next steps? What is the plan for the remainder of 2009 and 2010?**

Congress hopes that the health care reform debate will be completed by the end of calendar year 2009. With this massive endeavor out of the way, committee staff and Members who have spent almost the entire year working around the clock on health care reform will be freed up to consider other health-related legislation. All of the SMA community's efforts for the remainder of 2009 will be in preparation to step into this "void" and make real progress later this year once health care reform is completed and in 2010.

Later this year or beginning in January 2010, the congressional committees with jurisdiction over the SMA Treatment Acceleration Act (the House Energy & Commerce Health Subcommittee and the Senate Health, Education, Labor and Pensions (HELP) Committee) are expected to entertain health-related bills with broad, bipartisan support. The SMA Treatment Acceleration Act falls under this broad categorization; however, there are hundreds of such bills and the Committees will likely take up only those bills that are entirely "non-controversial", meaning that every member of the committee is comfortable with the legislation or does not have major objections to its consideration. In order for the SMA Treatment Acceleration Act to be considered in this process, the SMA community must continue to engage lawmakers to educate them about the Act and to build our base of support so that we are prepared to receive Committee consideration when the time comes.

**Q4: What can I do to help?**

Please continue to engage every Member of Congress in support of the SMA Treatment Acceleration Act by writing and calling your Senators and Representatives. Personalized calls and letters to Members of Congress from the SMA community are the most effective methods of advocating for the SMA Treatment Acceleration Act. In the immediate months, as health care reform continues to dominate the political stage, you should continue to ask friends, family and community members to write letters of support to their Members of Congress encouraging them to cosponsor the legislation. This outreach will lead to more cosponsors and will impact the decision makers on the committees of jurisdiction.

## Current Cosponsors:

### **In the House (57):**

#### **Rep. Patrick Kennedy (RI) Sponsor**

Rep. Rodney Alexander (LA)  
Rep. Tammy Baldwin (WI)  
Rep. Rick Boucher (VA)  
Rep. G.K. Butterfield (NC)  
Rep. Kathy Castor (FL)  
Rep. Yvette Clarke (NY)  
Rep. Charles Dent (PA)  
Rep. John Fleming (LA)  
Rep. Jeff Fortenberry (NE)  
Rep. Bob Goodlatte (VA)  
Rep. Gene Green (TX)  
Rep. Gregg Harper (MS)  
Rep. Brian Higgins (NY)  
Rep. Tim Holden (PA)  
Rep. Walter Jones (NC)  
Rep. James Langevin (RI)  
Rep. Carolyn Maloney (NY)  
Rep. Thaddeus McCotter (MI)  
Rep. Cathy McMorris Rodgers (WA)  
Rep. Tom Price (GA)  
Rep. Harold Rogers (KY)  
Rep. Bobby Rush (IL)  
Rep. Joe Sestak (PA)  
Rep. Patrick Tiberi (OH)  
Rep. Debbie Wasserman Schultz (FL)  
Rep. Joe Wilson (SC)  
Rep. Frank Wolf (VA)  
Rep. C.W. Bill Young (FL)

#### **Rep. Eric Cantor (VA) Sponsor**

Rep. Spencer Bachus (AL)  
Rep. Earl Blumenauer (OR)  
Rep. Bruce Braley (IA)  
Rep. Lois Capps (CA)  
Rep. Donna Christensen (VI)  
Rep. Jim Cooper (TN)  
Rep. Steve Driehaus (OH)  
Rep. Randy Forbes (VA)  
Rep. Barney Frank (MA)  
Rep. Bart Gordon (TN)  
Rep. John Hall (NY)  
Rep. Stephanie Herseth Sandlin (SD)  
Rep. James Himes (CT)  
Rep. Steve Israel (NY)  
Rep. Peter King (NY)  
Rep. Zoe Lofgren (CA)  
Rep. Eric Massa (NY)  
Rep. Mike McIntyre (NC)  
Rep. Gregory Meeks (NY)  
Rep. Adam Putnam (FL)  
Rep. Steve Rothman (NJ)  
Rep. Bobby Scott (VA)  
Rep. Bennie Thompson (MS)  
Rep. Edolphus Towns (NY)  
Rep. Lynn Westmoreland (GA)  
Rep. Robert Wittman (VA)  
Rep. David Wu (OR)

### **In the Senate (15):**

#### **Sen. Debbie Stabenow (MI) Sponsor**

Sen. Sherrod Brown (OH)  
Sen. Saxby Chambliss (GA)  
Sen. Kay Hagan (NC)  
Sen. Frank Lautenberg (NJ)  
Sen. Jack Reed (RI)  
Sen. Arlen Specter (PA)  
Sen. Roger Wicker (MS)

#### **Sen. Johnny Isakson (GA) Sponsor**

Sen. Richard Burr (NC)  
Sen. Kristen Gillibrand (NY)  
Sen. John Kerry (MA)  
Sen. Patty Murray (WA)  
Sen. Bernard Sanders (VT)  
Sen. Sheldon Whitehouse (RI)