



June 26, 2009

Greetings SMA families, researchers and friends:

First and foremost, thank you for all you have done to help us increase awareness and attention to finding a treatment or cure for Spinal Muscular Atrophy (SMA). We are especially grateful to all of you who have taken the time to contact your Members of Congress in support of The SMA Treatment Acceleration Act of 2009 (H.R. 2149/S. 1158).

Thanks to our grassroots efforts, 17 Members of the House of Representatives and 4 Senators have now signed on to the SMA legislation. In order to keep this bill moving through the legislative process, we need to continue to grow the number of cosponsors of the bill. Our goal during the next two months is to encourage previous cosponsors from the 110<sup>th</sup> Congress to sign on to the bill again, while at the same time adding new members to the ranks. A list of our current cosponsors, as well as our target House and Senate cosponsors from the 110<sup>th</sup> Congress, are provided below. **More than ever, we need your help!** **PLEASE contact your Members of Congress to ask them to cosponsor the SMA Treatment Acceleration Act.**

Additionally, the July 4<sup>th</sup> recess which begins next Monday, June 29<sup>th</sup> is an ideal time for families to arrange meetings with their Senators and Representatives in their state and district offices. District meetings offer a unique opportunity in the middle of Congress's long summer work period to focus Members' attention on the SMA bill while they are away from the constant demands of their work on healthcare reform and other issues in Washington. **PLEASE contact your Senators and Member of Congress' state and district offices and request to meet with them over the July 4<sup>th</sup> recess.**

As most of you are aware, the SMA Treatment Acceleration Act of 2009, introduced in the U.S. House of Representatives by Congressmen Patrick Kennedy (RI) and Eric Cantor (VA) and in the U.S. Senate by Senators Debbie Stabenow (MI) and Johnny Isakson (GA), provides federal support to complement the substantial private funding that is being invested to find a treatment for SMA. Passage of this landmark legislation will enable scientific investigators to mount national clinical trials and demonstrate that potential treatments are safe and effective for SMA patients.

**THANK YOU AGAIN for your help for all those with SMA!**

Sincerely,

Kenneth Hobby  
Families of SMA

Martha Slay  
FightSMA

Annie Kennedy  
MDA

Cynthia Joyce  
SMA Foundation

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NOTE: If you have any questions about the "SMA Treatment Acceleration Act of 2009" or for more information, please feel free to contact any one of our Government Affairs staff:

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## 111<sup>th</sup> Congress Cosponsors

### House

Patrick Kennedy (RI)  
Eric Cantor (VA)  
Steve Driehaus (OH)  
John Fleming (LA)  
Greg Harper (MS)  
Jim Langevin (RI)  
Carolyn Maloney (NY)  
Thaddeus McCotter (MI)  
Cathy McMorris Rodgers (WA)  
Gregory Meeks (NY)  
Joe Sestak (PA)  
Patrick Tiberi (OH)  
Edolphus Towns (NY)  
Joe Wilson (SC)  
Robert Wittman (VA)  
Frank Wolf (VA)  
David Wu (OR)  
Bill Young (FL)

### Senate

Debbie Stabenow (MI)  
Johnny Isakson (GA)  
Sherrod Brown (OH)  
Bernard Sanders (VT)  
Sheldon Whitehouse (RI)

## 110<sup>th</sup> Congress Cosponsors Targets

### House

Rep. Rodney Alexander (LA)  
Rep. Jason Altmire (PA)  
Rep. Brian Baird (WA)  
Rep. Tammy Baldwin (WI)  
Rep. Timothy Bishop (NY)  
Rep. Earl Blumenauer (OR)  
Rep. Dan Boren (OK)  
Rep. Rick Boucher (VA)  
Rep. G.K. Butterfield (NC)  
Rep. Lois Capps (CA)  
Rep. Christopher Carney (PA)  
Rep. Kathy Castor (FL)  
Rep. Yvette Clarke (NY)  
Rep. Jim Cooper (TN)  
Rep. Norman Dicks (WA)  
Rep. Anna G. Eshoo (CA)  
Rep. Randy Forbes (VA)  
Rep. Bob Goodlatte (VA)  
Rep. Bart Gordon (TN)  
Rep. Gene Green (TX)  
Rep. Ralph Hall (TX)  
Rep. Brian Higgins (NY)  
Rep. Peter Hoekstra (MI)  
Rep. Jay Inslee (WA)  
Rep. Henry Johnson (GA)  
Rep. Dale Kildee (MI)  
Rep. Ron Kind (WI)  
Rep. Jack Kingston (GA)  
Rep. Mark Kirk (IL)  
Rep. Zoe Lofgren (CA)  
Rep. Nita Lowey (NY)  
Rep. Edward Markey (MA)  
Rep. Jim Marshall (GA)  
Rep. Michael McCaul (TX)  
Rep. John McHugh (NY)  
Rep. Mike McIntyre (NC)  
Rep. Candice Miller (MI)  
Rep. James Moran (VA)  
Rep. Tim Murphy (PA)  
Rep. Jerrold Nadler (NY)  
Rep. Grace Napolitano (CA)  
Rep. Donald Payne (NJ)  
Rep. Collin Peterson (MN)  
Rep. David Price (NC)  
Rep. Tom Price (GA)  
Rep. Ileana Ros-Lehtinen (FL)  
Rep. Mike Ross (AR)  
Rep. Steve Rothman (NJ)  
Rep. Lucille Roybal-Allard (CA)  
Rep. Tim Ryan (OH)  
Rep. Bobby Scott (VA)  
Rep. Pete Stark (CA)  
Rep. Cliff Stearns (FL)  
Rep. Debbie Wasserman Schultz (FL)  
Rep. Lynn Westmoreland (GA)  
Rep. Charles Wilson (OH)  
Rep. Lynn Woolsey (CA)

### Senate

Sen. Jeff Bingaman (NM)  
Sen. Barbara Boxer (CA)  
Sen. Maria Cantwell (WA)  
Sen. Robert Casey (PA)  
Sen. Saxby Chambliss (GA)  
Sen. Dianne Feinstein (CA)  
Sen. John Kerry (MA)  
Sen. Frank Lautenberg (NJ)  
Sen. Joseph Lieberman (CT)  
Sen. Robert Menendez (NJ)  
Sen. Barbara Mikulski (MD)  
Sen. Patty Murray (WA)  
Sen. Jack Reed (RI)  
Sen. Jim Webb (VA)