



Advocacy Successes in 2004

PPMD has enjoyed tremendous support from our Congressional champions. For the third time in four years, PPMD hosted a fly-in to Capitol Hill in March 2004. Your efforts earlier this year are close to paying off. **A record 68 Congressmen and 15 Senators signed letters supporting PPMD's Fiscal Year 2005 appropriations requests.**

PPMD's most important bill is the Fiscal Year 2005 Labor, HHS and Educations Appropriations. The House has passed its version of the legislation and the key Senate Committee has passed a similar bill. We must remain vigilant because anything can happen, but PPMD has made significant strides so far. **Our successes to date are:**

- Senate funds three new centers and doubles funding for existing Centers; House funds additional Centers of Excellence and increases funding for existing Centers.
- House increases the NIH "commitment to Duchenne MD translational research and clinical trials, separate from support for the centers of excellence program." Senate has similar language;
- House has "accelerated model for funding Duchenne MD translational research" at the NIH. Senate has similar language;
- House and Senate enhance NIH research "surrounding pulmonary and cardiac complications;"
- House and Senate have \$1.5 million for CDC's Duchenne MD (DMD) surveillance program, **including:**
 - **a \$500,000 earmark for PPMD** "to initiate a coordinated education and outreach initiative" with CDC;
- House and Senate call on AHRQ "to study and develop recommendations on the need for standards of care;" and
- House and Senate encourage an AHRQ workshop on standards of care and require coordination with national advocacy organizations.

In addition, PPMD supported a multi-million dollar request for a Congressional earmark out of the Department of Defense's Health Research program. This bill is already passed into law, and there is a \$2.5 million earmark for DMD research.

Our success on Capitol Hill is rooted in families and advocates visiting and lobbying in Washington, D.C. PPMD and its parent advocates continue to make a sizeable impact in Washington on behalf of the children who suffer from Duchenne and Becker MD and their families. Clearly, advocacy conferences in Washington are instrumental to our success. Our accomplishments speak for themselves, but we still have not achieved all of our federal goals in combating the disorder. Please continue to stay involved so we can continue to have an effective voice in Congress and at NIH, CDC, DoD and other agencies relevant to MD.

Mark your calendars...

**The 2005 Advocacy Conference is set for March 6, 7 and 8th.
We hope to see you there!**