

Advocating En Masse at Washington Days

National Hemophilia Foundation

Great Lakes Hemophilia Foundation
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National Hemophilia Foundation e-notes



Wisconsin Advocates: Stacy Brault, Sandy Lampman, Congresswoman Tammy Baldwin, Kimberly Haugstad and Michael O'Connor

Approximately 300 people traveled to Washington, D.C. on February 24-25, 2010 to participate in the National Hemophilia Foundation's Washington Days annual advocacy event. When meeting with their senators and representatives participants focused on two key issues: maintaining federal funding for the U.S. Centers for Disease Control and Prevention's (CDC) hemophilia program and garnering support for the private insurance reforms included in health reform.

Washington Days provides the bleeding disorders community the opportunity to educate Congress about the issues affecting us and to spotlight the importance of the hemophilia treatment center (HTC) network. This year's effort is particularly important because President Obama's FY 2011 proposed budget for the CDC zeroes out the hemophilia program, reallocating the money for a "public health approach to blood disorders." It is not clear what the CDC intends to do with this new approach and there is no guarantee that existing hemophilia program activities will be adequately supported. Participants this year advocated for the reinstatement of the CDC's hemophilia program to ensure that access to care at HTCs is not jeopardized.

Efforts on the health reform front were directed at advocating for key private insurance market reforms to be included in the final reform legislation, which will benefit individuals with bleeding disorders and other high-cost, chronic and rare conditions. Participants requested that the final health reform legislation have the strongest possible patient protections and ensure access to health insurance plans for individuals with high medical costs. We respectfully requested that the final health reform legislation be applicable to all insurance plans--existing and new plans--and that it include the immediate elimination of lifetime and annual caps, and other key reforms such as the elimination of pre-existing conditions exclusions.

For more information on the funding issue regarding the CDC's hemophilia program be on the lookout for e-mail blasts from NHF's policy department. To stay up to date on health reform and opportunities to get involved, please visit the Advocacy section at www.hemophilia.org.

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