

NHF Washington Days 2010 Talking Points

Introduce Yourself

- Ask if the member/staffer is familiar with hemophilia. If not, share hemophilia 101 (i.e., background on bleeding disorders) – this should only take a few minutes. The person who is the constituent (lives in the member's district) should take the lead.

Hemophilia Treatment Centers (HTCs)

- We discuss the importance of HTCs every year, **but this year there is a problem**: President Obama's FY 2011 budget for CDC zeroes out the hemophilia program. The budget reallocates 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. Eliminating the hemophilia program could jeopardize access to care at HTCs.
- The CDC's hemophilia program provides funding for research, outreach and education activities. CDC funds also provide critical support for HTCs, for prevention and surveillance activities such as the Universal Data Collection (UDC) Project.
- Share the name of your HTC (and hospital if it's located in one). Explain what an HTC is and why your HTC is important to you.
- More than 75% of the bleeding disorders community receives care from HTCs. Studies have shown a 40% reduction in mortality and morbidity associated with HTC care.

Request: Maintain funding for the hemophilia program at the CDC. Ask Member to sign letter to Appropriations Committee supporting funding for HTCs. If Member serves on Appropriations Committee (noted on your schedule), then ask him/her to support maintaining the hemophilia program in Committee. Note: supporting program funding is not the same as requesting an earmark; signing this letter does not require earmark disclosure.

Health Reform Priorities of the Bleeding Disorders Community

- If you are meeting with a Democratic Member – thank them for their support for legislation to reform the healthcare system and provide access to health insurance to all Americans.
- If you are meeting with a Republican Member – recognize that they do not support the bill, but many of them have supported private insurance market reforms.
- Mention that you recognize that health reform negotiations have stalled, but that you want to share with them NHF's priorities (letter is in folder). If a bill passes, we will need to work with Congress to see that it is implemented effectively.
- Explain that Americans with bleeding disorders and other chronic conditions need healthcare reform. Share ways in which the current system does not meet your needs, such as difficulty in obtaining adequate insurance coverage. NHF supports the private insurance reforms included in the bills to prevent insurance company abuses.
- Highlight the need to eliminate lifetime and annual caps. NHF and the bleeding disorders community have taken the lead on these issues. Explain why lifetime and annual caps pose particular problems for people with bleeding disorders. NHF supports the immediate elimination of lifetime and annual limits. Share the letter from the Raise the Caps Coalition.
- Mention that NHF also supports private insurance reforms (definitions included in your folder) to:
 - establish guaranteed issue and renewal;
 - implement modified community rating;
 - prohibit rescissions except for fraud;
 - eliminate pre-existing conditions exclusions;
 - limit out-of-pocket expenses;
 - extend coverage for dependents

Request: Support the strongest possible patient protections in the final health reform bill, including the immediate elimination of lifetime and annual caps.

Thank them for their time and consideration.