

NHF Washington Days 2011 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.
- Explain that there are two reasons for your visit: 1) You are concerned with the proposals to significantly cut the budgets of the health programs that support HTC's. 2) You want to make sure that the private insurance reforms that were included in the health reform legislation not be repealed.

Federal Hemophilia Programs

- Share the name of your HTC (and hospital if it's located in one). Key Points to Make on why HTC's are important:
 - Hemophilia is a rare disorder, so it is critically important to have access to healthcare providers that are knowledgeable about the disease and the most effective treatments
 - Hemophilia puts you at risk of significant disability if not treated quickly and effectively. Describe what happens when a joint bleed occurs. If you are on prophylaxis talk about how treatments prevent bleeds from occurring.
 - Hemophilia is extremely costly to treat - average costs of treatments for an individual with severe hemophilia can be \$300,000 or up to \$1 million if an inhibitor develops.
- HTC's provide healthcare services, treatments and education to allow you to manage your hemophilia effectively by providing access to hematologists, surgeons, and dentists that are experts in hemophilia as well as social workers and nurse practitioners.
- More than 75% of the bleeding disorders community receives care from HTC's. Studies have shown a 70% reduction in mortality and morbidity associated with HTC care.
- There are two federal programs that provide funding to the HTC's: one at the Maternal and Child Health Bureau, which funds coordination of care services that are critical to managing the high costs of the disease. The other program is at the CDC; it funds prevention and blood safety programs.

Request: Ask the Member to oppose cuts to the Maternal and Child Health programs and the CDC in 2011 and ask that funding be maintained in 2012. Note: we are not asking for any program increases, just that the current funding be maintained.

Upholding Patient Protections in Health Care Reform

- Explain that Americans with bleeding disorders and other chronic conditions will benefit from health care reform in real and tangible ways. Share ways in which the previous system did not meet your needs, such as difficulty in obtaining adequate insurance coverage.
- Highlight the significance of eliminating lifetime and annual caps and pre-existing condition exclusions. Explain why these practices posed particular problems for people with bleeding disorders.
- NHF supports the private insurance reforms included in the Affordable Care Act to prevent insurance company abuses, such as:
 - 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 dependent

Request: Support and maintain the private insurance reforms included in the Affordable Care Act, which allow individuals with high-cost conditions, such as hemophilia, access to adequate and affordable coverage.

Thank them for their time and consideration.