



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

NHF Washington Days 2009 Talking Points

Introduce Yourself

- Introduce yourself. Ask if member/staffer is familiar with hemophilia. If not, share hemophilia 101 basic facts – this should only take a few minutes. It can be helpful to remind your audience of some basic facts.

Health Reform

- Americans with bleeding and clotting disorders and other chronic conditions want and need healthcare reform. We need:
 - Access to affordable healthcare coverage with no pre-existing condition clauses and no lifetime or annual caps.
 - Access to the proven model of specialized comprehensive care and to the full range of approved therapies (i.e., all clotting factor treatments).
 - Protection for the physician's ability, in consultation with the patient, to determine the best treatment regimen for that patient.
 - Access to treatment that supports not only physical health but also a high quality of life.
- Share ways in which the current system does not meet your needs, i.e., difficulty in obtaining adequate insurance.

Lifetime Caps

- Majority of Americans with insurance face lifetime caps of \$2-\$3 million. Some caps are even lower.
- This is a major problem for people with high-cost chronic conditions like hemophilia, where costs of factor can be \$250,000 per year or higher. The development of an immune response to clotting factor called an inhibitor or other complications can drive the cost in a given year to \$1 million or more. Families are often forced to make drastic choices that affect their employment, place of residence or even family life in order to maintain coverage.
- Discuss the costs of your care – have you hit a cap or come close? Have you been concerned that you would? Have worries about a cap ever affected treatment decisions?

The Health Insurance Coverage Protection Act (S. 442/H.R. 1085):

- Phases in an increase to a minimum of \$10 million for lifetime caps on private insurance, with an inflationary update in future years;
- Exempts small employers with fewer than 20 employees, but insurers must offer a plan with a \$10 million cap or higher to small employers who request it;
- Allows people with bleeding disorders and other high-cost chronic conditions who have private insurance to maintain their coverage and not have to seek public assistance such as Medicaid or state high-risk pools.
- Senate co-sponsors: Senators Dorgan (D-ND) & Snowe (R-ME)
- House co-sponsors: Reps Eshoo (D-CA), Langevin (D-RI), Sutton (D-OH), Altmire (D-PA) & Kildee (D-MI)

Request: Ask Member to co-sponsor S. 442/H.R. 1085, the Health Insurance Coverage Protection Act. To do so, contact Mina Addo with Senator Dorgan/Scott Nolen with Senator Snowe or Erin Katzelnick-Wise with Representative Eshoo.

Hemophilia and Thrombophilia Treatment Centers (HTCs)

- Share the name of your HTC (and hospital if it's located in one). Explain what an HTC is, including the unique and effective model of comprehensive care it provides. What services do you and/or a family member receive from your HTC on clinic day and throughout the year? Why is your HTC 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.
- HTCs receive funding from two federal agencies: the Centers for Disease Control and Prevention (CDC, to support prevention and surveillance) and the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (to support nursing, rehabilitative and social services not reimbursed by insurance). The population served at many HTCs has doubled in the last 10 years, but funding has remained static; in some cases, it has been cut. Current funding to support HTCs is about \$11 million.

Request: Maintain federal funding for the national network of 140 HTCs. 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 full funding in Committee.