



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

TALKING POINTS FOR INCREASED HTC FUNDING TO BETTER SERVE WOMEN WITH BLEEDING DISORDERS

Issue: To support a \$3 million increase in funding in the 2009 Labor, HHS Appropriations Bill for the Centers for Disease Control and Prevention's hemophilia program, allowing hemophilia treatment centers (HTCs) to better serve women with bleeding disorders.

Status of Funding Increase and NHF Request

Last year:

Congressman Patrick Kennedy (D-RI) took the lead in inserting funding for the HTCs in the 2008 appropriations bill. Kennedy, with the support of Congressman Steve Israel (D-NY) and more than 20 members of Congress who signed a letter of support for funding, was successful in getting close to \$900,000 for HTCs. However, this increase in funding was not included in the Senate Labor HHS Appropriations Bill or in the final bill signed by the President.

This year:

House and Senate: Ask your Senators and Congressman or Congresswoman to support an increase in funding for HTCs in the 2009 Labor, HHS Appropriations Bill for the Centers for Disease Control and Prevention's hemophilia program.

Important Note: This request for additional funding is not an earmark. The money will go to the hemophilia program at the CDC. HTCs must apply for funds and meet CDC requirements.

Why This Legislation is Important to the Bleeding Disorders Community

- Explain what a hemophilia treatment center (HTC) is, including the unique and effective model of comprehensive care it provides. What services do you, a family member, or friend receive from your HTC on clinic day and throughout the year?
- Share the name of your HTC (and hospital if it's located in one). Why is it important to you and others in the community to have access to an HTC?
- Contrast the care received at an HTC with care received outside the network. Have you had any bad experiences? Has your HTC care kept you out of the emergency room?

- More than 75% of the hemophilia community receives care from HTC. Studies have shown a 40% reduction in mortality and morbidity associated with HTC care.
- Mention how women with bleeding disorders are the fastest growing population served by the HTCs, but the funding has not increased to meet the need.

Note: Women with bleeding disorders should relate their personal experiences, including difficulties in being properly diagnosed and in receiving appropriate treatment.

What a \$3 Million Increase Would Do

- The funding increase will enable HTCs to better serve women with bleeding disorders.
- Current CDC funding for HTCs is \$6.8 million per year. There has been relatively no increase in the last 10 years. Many of the services that HTCs provide are not covered by insurance, which is why federal support is so important.
- Women are the fastest growing population treated in HTCs, which leads to greater demand for services.
- The increased funding would allow HTCs to evaluate the best ways to identify, diagnose and treat women in their community. Efforts could include outreach to school nurses, pediatricians, and rural health clinics, and extending social work, genetic counseling and education services to women.

More Facts about Women with Bleeding Disorders and HTCs

- The most common women's bleeding disorder is von Willebrand disease (VWD) – the CDC estimates up to 1%-2% of the population is affected. Women with VWD experience heavy menstrual periods and prolonged bleeding following injury, surgery and childbirth.
- Of the 30,000 women in the U.S. who have a hysterectomy due to heavy bleeding each year, many could have been treated medically.
- It takes an average of 16 years from the onset of symptoms until diagnosis for a woman with VWD.
- For women, HTCs provide comprehensive evaluations and genetic counseling, coordinate care with primary care and ob/gyn physicians, and manage surgeries and childbirth. Women with bleeding disorders are at greater risk for complications during childbirth and surgery and need the expertise of the HTC staff.