



MEDICAL NEWS	1
BLOOD SAFETY NEWS	3
ADVOCACY UPDATE	6
NHF NEWS	12

MEDICAL NEWS

FDA Approves Baxter's Albumin-Free Treatment for Hemophilia A Product will Begin Shipping This Week

August 20, 2003

Baxter Healthcare Corporation announced recently that the U.S. Food and Drug Administration had granted approval for their new plasma and albumin-free recombinant factor VIII product for the treatment of hemophilia A. The product, which is being marketed under the name ADVATE, is the first factor VIII made without any added human or animal plasma proteins or albumin in the cell culture process, purification and final formulation. Other recombinant factor VIII therapies either use human plasma protein solutions and/or other human- or animal-derived materials during processing, or add human albumin for stabilization. The reason for eliminating these substances from the manufacturing process is safety. Although currently available products have been proven over time to be safe, human and animal material have the potential to carry disease-causing viruses or pathogens, including those which may be unknown.

Commenting on the product approval, NHF President Gina S. Shreve said "NHF strongly supports development of new products with improved safety and efficacy and welcomes expanded product choice."

The first shipments of the new product, which is processed in Baxter's biotechnology facility in Neuchâtel, Switzerland, will arrive at homecare companies and other distributors later this week, according to a Baxter spokesperson. Baxter has set up a special website, www.advate.com, and a toll-free number, 1-888-4ADVATE, to answer questions and provide consumers, health-care providers, and other interested parties with more information about the product.

Hepatotoxicity Linked to Antiretroviral HIV-1 Protease Inhibitor Therapy

August 11, 2003

In a recent study published by scientist Mark S. Sulkowski in *Seminars in Liver Disease*, hepatotoxicity has been linked to antiretroviral therapy with HIV-1 protease inhibitors.

"Human immunodeficiency virus 1 (HIV-1) protease inhibitors are important components of highly active antiretroviral therapy (HAART) and have had a profound impact on the natural history of HIV and AIDS. However, in the era of HAART, drug-induced hepatotoxicity or liver injury has emerged as an important potential complication of combination antiretroviral therapy, particularly those regimens containing protease inhibitors (PIs)," Sulkowski said.

The study goes on to say that "liver injury has been associated each of the six PIs currently approved by the U.S. Food and Drug Administration (FDA), most commonly with administration of full dose ritonavir (600 mg bid or 400 mg bid with saquinavir). However, this regimen has been largely replaced by the use of low-dose ritonavir (<200 mg bid) to pharmacologically 'boost' other PI's, such as lopinavir or indinavir, which have not been associated with an increased risk of hepatotoxicity compared with other PIs. Co-infection with hepatitis C virus (HCV) and B virus (HBV) remains an important risk factor for the development of HAART-associated liver injury."

"Although studies indicate that co-infected patients can be safely treated with PIs, such patients should be closely monitored," concluded Sulkowski. "In addi-

tion, although unsubstantiated, some experts recommend evaluation or treatment, or both, of underlying chronic viral hepatitis prior to the initiation of antiretroviral therapy. Further research is needed to understand the etiopathogenesis of PI-associated liver injury, particularly among patients with hepatitis B or C infection."

Source: *AIDS Weekly*

Mothers of People with Hemophilia Protected From Heart Diseases

August 2, 2003

A paper published recently in the British medical journal *The Lancet* reports on the apparent protective effect of carrier status for women against ischemic heart disease. The paper, entitled "Decreased mortality of ischemic heart disease (ICD) among carriers of hemophilia," was authored by Rits Rosendaal, a professor at Leiden University, the Netherlands, and others. The researchers followed up a cohort of 1,012 mothers of known people with hemophilia in the Netherlands from birth to death. Deaths from ICD were reduced by 36 percent (39 observed deaths; 60 to 53 expected).

To determine whether asymptomatic, decreased coagulability protects against ischemic cardiovascular events, the researchers compared mortality in gene carriers with that in the general population. To do so, they assessed death rates of mothers between 1861 and 2001. The women in the study were selected through their offspring. Although hemophilia can arise in some patients from a new mutation—either in women or in men—only about 40 percent of cases are isolated hemophilia cases. That is, they are without a family history of the disease. "Results of this investigation," Rosendaal summed up, "show that the mild decrease in blood coagulation that hemophilia carriers have affects the risk of heart attacks. This finding re-emphasizes the role of clotting and changes in clotting in the development of myocardial infarction. In the future it may have implications for prevention of this disease."

Source: *The Lancet*

Bayer Biological Products Announces First Recipients of Bayer Hemophilia Awards

July 7, 2003

Bayer Biological Products (BP) recently announced the first recipients of the Bayer Hemophilia Awards program grants. The 24 recipients, who hail from 10 countries, will receive grants for basic and clinical research and educational proposals in the field of hemophilia. The program, which was initiated in 2002, will provide annual grants totaling \$2.75 million to early career investigators, fellows in training and other hemophilia care professionals. Awarded proposals were selected by a 12-member Grant Review and Award Committee, developed collaboratively between Bayer BP and the World Federation of Hemophilia (WFH).

Recipients were honored in July at a special reception and dinner at the XIXth Congress of the International Society for Thrombosis and Haemostasis in Birmingham, England. The new cycle for accepting applications for 2004 awards is now beginning. More complete information on the Bayer Hemophilia Awards Program, award categories, and submission processes available at www.bayer-hemophilia-awards.com.

Source: Bayer release

B L O O D S A F E T Y N E W S

Unit of Blood Donated in Saskatchewan Becomes the First in Canada to Test Positive for West Nile Virus; Demonstrates Effectiveness of Roche Test

July 28, 2003

Canadian Blood Services' new screening test for West Nile virus has had its first positive result—a unit of blood that was donated in Saskatchewan on July 22. A sample taken from the donated blood tested positive at Canadian Blood Services' West Nile virus laboratory in Calgary, and supplementary testing performed at the organization's National Testing Laboratory in Ottawa confirmed the result late this afternoon. The donor and officials from Saskatchewan Public Health

have been notified of the test results. The unit of donated blood has been withdrawn from inventory and the donor will not be eligible to donate blood again for 56 days, at which time the virus will no longer be present in the blood.

"This result shows that our West Nile virus test is doing exactly what it was designed to do - helping reduce the risk that the virus will enter the blood supply," said Dr. Graham Sher, Chief Executive Officer of Canadian Blood Services.

Canadian Blood Services uses the commercial West Nile virus test developed by Roche Diagnostics. The Roche test uses the same technology that is already used to test every unit of blood for HIV and hepatitis C. It has been introduced as an investigational test in order to make it available at the earliest time, and therefore its effectiveness will continue to be monitored and enhanced. It is standard practice to introduce tests at the earliest possible date in order to provide the highest safety possible at the time and to make incremental improvements over time.

Source: Canada Newswire English

West Nile Virus Testing Implemented

July 25, 2003

West Nile virus (WNV), the mosquito-borne flavivirus, infected approximately 4,000 individuals throughout 39 states and the District of Columbia during 2002. Prior to 2002 it had been thought that WNV could be transmitted to human beings only via infected mosquitoes. However, extensive investigations conducted last year revealed blood-borne transmission in at least 21 people in 2002.

To reduce the risk of WNV transmission by blood and blood products, nationwide WNV testing began on or about July 1, 2003, after a year of unprecedented collaboration among U.S. public health officials, blood bank organizations and blood donor test developers. The test is being employed and endorsed by the American Red Cross, America's Blood Centers, American Association of Blood Banks and the Armed Services Blood Program.

Public health service officials, blood bank organizations and test developers met throughout last year to discuss strategies for development and implementation of a blood test to identify potential blood donors infected with WNV. A blood test was needed because 80 percent of individuals with WNV are asymptomatic.

The WNV blood test allows for direct detection of the genetic material of the WNV using nucleic acid amplification testing, or NAT—the process used to further reduce the risk of HIV and hepatitis C transmission by transfusion. In order to implement WNV testing for the 2003 mosquito season, the Food and Drug Administration is allowing national deployment of investigational tests—a similar approach to that taken for NAT to detect HIV and HCV.

Testing currently is not being implemented for source plasma donors, as current evidence suggests, but does not fully confirm, that WNV is inactivated by the manufacturing processes used to produce plasma-derived products such as hemophilia clotting factor. The Centers for Disease Control and Prevention the FDA continue to monitor for WNV cases in the general population and in the bleeding disorders population. In addition, FDA continues to work with manufacturers of clotting factor to complete testing to confirm viral inactivation by the manufacturing processes used for clotting factor and other plasma-derived products.

Source: *Associated Press*

As New Viruses Emerge, Health Officials Scramble to Make Blood Supply Safer

July 14, 2003

Increased international travel and growing human contact with creatures of forests, swamps and jungles create more opportunities for new and potentially lethal infections to sweep the globe—and contaminate the blood supply. West Nile virus, SARS and monkeypox have all surfaced recently in the United States, and at least one, West Nile, can potentially be transmitted through blood. Health officials dealing with this reality must determine for each emerging infections whether it can be transmitted this way and whether the particular threat warrants the development and implementation of new screening tests.

West Nile virus, for example, was first identified in this country four years ago in New York. It wasn't until last fall, however, that health officials discovered that several organ-transplant recipients had been infected by contaminated blood given by transfusion to organ donors. In November, the Food and Drug Administration (FDA) urged test manufacturers to develop blood tests that could directly detect the mosqui-

to-borne virus in time for the 2003 mosquito season. By July 1 two companies had met the challenge.

Public health officials consider that pace extraordinary, and the test is just now being used by blood donation centers nationwide. Things moved more quickly than usual for two reasons. The West Nile virus had been genetically sequenced, so scientists had the virus' entire blueprint in hand. And both companies had experience with polymerase chain-reaction technology, which makes millions of copies of tiny gene fragments so they're easier to use in research.

Roche Molecular Diagnostics in Pleasanton, California, which began clinical trials on June 16, said its West Nile test also detects viruses for Japanese encephalitis, St. Louis encephalitis and Murray Valley encephalitis. Clinical trials of the other West Nile test, developed by Chiron Corp. of Emeryville, California, and Gen-Probe Inc. of San Diego, began June 18.

Decisions about whether to screen for a particular disease are made by the FDA, based on disease surveillance from the federal Centers for Disease Control and Prevention (CDC), with input from the blood-collection industry. The CDC has been busy in recent years monitoring U.S. outbreaks of anthrax, West Nile, SARS and monkeypox. From the time the first cases are reported, CDC epidemiologists scramble to determine how — and how easily — they're transmitted, said Dr. Matt Kuehnert, CDC's assistant director for blood safety. They also must determine whether they can be spread by someone who is infected but has no symptoms, or hasn't yet developed antibodies. With West Nile, 80% of infected people have no symptoms and could unwittingly donate contaminated blood.

Katz says the public health community is closely watching diseases transmitted to people from insects and animals in the developing world, because those could have an impact here. "Who knows what the next thing is that's going to come out of south China, central Africa or the Amazon Basin?"

At this point, donated blood is screened for HIV, hepatitis B, hepatitis C and syphilis, as well as HTLV-1, which causes leukemia and lymphoma, and the related HTLV-2 virus. West Nile recently joined the list. But with many diseases, finding a test that's specific enough to catch true cases and sensitive enough not to return too many false positives frequently remains elusive.

Antibody tests also have a built-in problem: Often, the body doesn't make antibodies for days to weeks after infection, so many cases can be missed. They are generally considered harder to develop because they need to be specific enough to identify only the disease in question, but also sensitive enough to pick up most cases. Nucleic acid tests, such as the West Nile test, go after tinier targets, so they are more specific and more sensitive early in the course of infection. In addition, officials must carefully balance the number of cases the screening will prevent against the amount of donated blood that will be lost due to false positives.

While on the lookout for emerging diseases, epidemiologists, federal regulators and the blood-collection industry also worry about detecting established diseases with the potential to cause severe illness and death, including:

*** Chagas disease.** Caused by a parasite rampant in Central and South America and spread most often by bites, Chagas causes fever, weakness and potentially fatal heart or brain infections. The FDA doesn't consider existing Chagas tests being used in places such as Brazil good enough.

* **Babesiosis.** An infection of red blood cells caused by a parasite, it's spread by the same deer ticks that spread Lyme disease. It destroys blood cells and produces fever, muscle aches and sometimes anemia. In the last two decades, about 30 cases have been spread through contaminated blood.

* **Malaria.** Caused by four species of the Plasmodium parasite and spread mostly by mosquito bites, malaria takes hold in the liver, then invades red blood cells, causing them to burst. Infection creates chills, high fevers and eventually may produce anemia and an enlarged spleen. With no good test on the horizon, blood banks rely on donor health histories to screen out possibly infected people.

* **Variant Creutzfeldt-Jakob disease.** This human form of "mad cow" disease is a degenerative brain illness that typically starts with psychiatric symptoms that don't appear until years after contaminated beef is eaten. Death results within months to a year after symptoms appear. It's thought to be spread by prions, which are abnormal proteins, but scientists don't yet know if prions are present in blood.

Source: *Los Angeles Times*

ADVOCACY UPDATE

CMS Issues Draft Notice On AWP Revisions

August 15, 2003

The Centers for Medicare and Medicaid Services (CMS) issued a notice of proposed rulemaking on August 15, 2003, proposing four alternatives to the current average wholesale price (AWP) reimbursement formula used by Medicare to pay for Part B covered drugs, including hemophilia clotting factor. Under one proposed alternative, Medicare reimbursement for clotting factor could be reduced to as low as 80 percent of AWP in 2004 and potentially 64 percent of AWP in 2005. This reduction would be partially offset by the establishment of a \$0.05 per unit administration fee.

CMS repeatedly has stated it would revise Medicare drug payment by the end of 2003 if Congress failed to act on the issue. Congress currently is considering revising Medicare drug payment as part of its reconciliation of differing House and Senate versions of the Medicare prescription drug legislation. (See *NHF E-Notes*, June and August 2003 for details of the Congressional provisions.) Medicare currently reimburses for Part B covered drugs at 95 percent of AWP.

NHF is collecting information that will be used to respond to the proposed rule. The notice can be accessed on the CMS website at www.cms.hhs.gov. CMS is accepting comments on the notice until October 14, 2003.

CONFERENCE BEGINS ON MEDICARE DRUG BILL Reimbursement Changes Being Considered for Clotting Factor Drugs

July 7, 2003

House and Senate members have begun negotiations to reconcile or "conference" the two differing versions of the Medicare prescription drug plan passed in June by their respective chambers. The House-Senate conference is expected to extend into late September as Republicans and Democrats battle over key bill provisions.

The enactment of a Medicare drug plan would not have immediate implications on coverage and reimbursement of hemophilia clotting factor. The drug plan would not take effect until 2006. Currently cov-

ered drugs, such as clotting factor, would be excluded. Reimbursement of clotting factor in the home and hospital outpatient setting, however, might be altered under other provisions of the bill. NHF has worked with the Senate Finance Committee and the House Energy and Commerce and Ways and Means Committees to assist them in understanding the potential implications of changes in clotting factor reimbursement on the bleeding disorders community.

AWP Revisions

Currently, Medicare covers approximately 450 physician or self-administered drugs under Part B of the program and reimburses these drugs at 95 percent of the average wholesale price (AWP). Under the bill passed by the Senate, reimbursement for currently covered drugs, including clotting factor, would be reduced from 95 percent to 85 percent of AWP beginning January 2004. For subsequent years, the Secretary of Health and Human Services (HHS) would be required to determine whether the widely available market price differs from AWP. Reductions in payment of up to 15 percent a year could occur if the difference between AWP and the widely available price is found to be more than 15 percent. In recognition of the unique requirements of clotting factor, the Senate bill would also require the Secretary to develop a dispensing fee for clotting factor by January 2004 based on the General Accounting Office's report to Congress earlier this year.

The House-passed bill would revise payment for currently covered drugs by replacing AWP-based reimbursement with a competitive bidding system. Clotting factor would be exempt from the competitive bidding process and continue to be paid at 95 percent of AWP. The House bill calls for the Medicare Payment Advisory Committee to make recommendations in its 2004 report to Congress on payment of clotting factor, including the development of a dispensing fee.

HOPPS Provisions

The House and Senate bills also contain provisions that would affect reimbursement for clotting factor in the hospital outpatient setting. The hospital outpatient prospective payment system (HOPPS) was implemented in 2000 to replace the previous cost-based reporting and reimbursement system used to pay hospitals for their services to Medicare beneficiaries. The new system has been plagued with problems, particularly relating to payment for drugs that are expensive, low in volume, or independent from an outpatient service or surgery. NHF

has been successful in ensuring adequate payment for clotting factor drugs thus far, but system reforms are needed to avoid fluctuations in payment from year to year that might affect access to needed drugs.

The reform provisions in the House and Senate drug bills are somewhat similar in that both bills would set payment for hospital outpatient drugs at a percentage of AWP through 2006. The House bill would set reimbursement for 2004-2006 at the lower of 95 percent of AWP or a transition payment determined by whether the drug was sole source, multiple source with no generic competitors, or multiple source with generic brands available. The Senate bill would establish a new payment mechanism for 2005 and 2006 also based on a percentage of AWP and calls for a study of hospital costs to determine payment for 2007. Clotting factor drugs would be included in the revisions made by either of these proposals.

OIG Releases Report On HTCs

August 8, 2003

The Department of Health and Human Services' Office of the Inspector General (OIG) has released an evaluation of hemophilia treatment center (HTC) disposition of program income and patient choice policies. The eval-

uation was requested by the Health Resources and Services Administration (HRSA), which administers the Public Health Service drug discount pricing program (also known as the 340B program) as well as provides funding for HTC through the Maternal and Child Health Bureau. HTCs earn program income when they purchase blood-clotting factor and related drugs under the 340B program and resell these drugs to HTC patients. One of the conditions of participation in the 340B program is providing patient choice of providers for their drugs.

The OIG found that HTCs generally used program income for patient care and related activities, and had choice policies in place that allowed patients to obtain the blood clotting factor they needed from providers of their choice. Inappropriate use of program income related to HTC's parent company policies and overbilling of Medicaid, however, was noted at one of the six HTCs evaluated.

As a result of the evaluation, OIG recommended the development of program guidelines, improvement of monitoring of HTCs, and further work with the Centers for Medicare and Medicaid Services to ensure that the overpayment is refunded to the Medicaid program.

HRSA agreed with the OIG's findings and already has taken steps to implement the OIG recommendations.

The full report can be accessed at: <http://oig.hhs.gov/oas/reports/region3/30100350.pdf>

Minnesota Law Ensures People with Hemophilia Will Get Drugs Without Wait

August 15, 2003

The Minnesota Legislature passed a bill this session that ensures residents of that state with hemophilia still have immediate access to medication that is not on the Medicaid preferred drug list. If people on Medicaid need a drug or therapy that is not on the insurance's preferred list, they usually must get authorization from the state before drugs can be prescribed. That takes about one day.

The list of preferred drugs for Medicaid patients is determined by a committee chosen by the state health department. If two drugs have the same effects, the less-expensive one is put on the Medicaid preferred drug list, said Sen. Linda Berglin, DFL-Minneapolis and chair of the Health, Human Services and Corrections Budget Committee. Because the list of drugs waiting to be approved is so long, it will be at least two years before clotting factor therapies will be added. "This product is expensive no matter which you choose," Berglin said.

Several other states, including Texas, North Carolina, South Carolina, Nevada and Illinois, also have these types of exemptions for people with hemophilia. Recognizing the increasing number of decisions at the state level that impact this community, NHF is currently developing plans to expand its advocacy programs, including providing support for state-based efforts. NHF will continue to update the community on these efforts as they develop.

House and Senate Appropriations Bills Move Forward

Report Language Included on Bleeding Disorders Priorities

July 31, 2003

The House and Senate Labor, Health and Human Services (HHS), Education Appropriations Subcommittees with jurisdiction over the Federal hemophilia programs completed their FY2004 bills in late June. With the House passing its Labor, HHS Appropriations bill in July, next steps when Congress returns to Washington in September are passage of the bill by the Senate and conferencing of the two bills into a final package for presentation to the President.

Of importance to the bleeding disorders community within the Subcommittee's action is the increases in overall program funding for the Centers for Disease Control and Prevention, the Maternal and Child Health Bureau of the Health Resources and Services Administration, and the National Institutes of Health. In addition, NHF was successful in obtaining the inclusion of report language on bleeding disorders community priorities and funding requests in the reports accompanying the House and Senate bills. This language serves as a directive to the Federal agencies of Congress' expectations for the coming fiscal year.

NHLBI Director Lenfant Announces Retirement

Claude Lenfant, MD, director of the National Heart, Lung and Blood Institute (NHLBI), one of the Institutes of the National Institutes of Health (NIH), has announced his retirement, effective August 30, 2003. The longest-serving director of the NHLBI, Dr. Lenfant assumed his position in July 1982. During his tenure, Dr. Lenfant oversaw development and completion of major clinical trials that have had widespread impact on the ways in which diseases of the heart, lung and blood are treated and prevented.

Under his leadership, early research on the prevention of the transmission of blood-borne pathogens and the development of recombinant manufactured clotting factors was conducted. Dr. Lenfant also was among the first NIH directors to embrace the potential opportunities of genomic and proteomics research on disorders like hemophilia.

This research continues today within a robust NHLBI bleeding disorders research portfolio that includes support for research on gene-based therapies, inhibitor management, blood-borne diseases and von Willebrand disease.

NHF recognized Dr. Lenfant's contributions to the bleeding disorders community earlier this year with presentation of the Foundation's Dr. L. Michael Kuhn Award for outstanding service. Plans have not been formalized for Dr. Lenfant's replacement. Deputy Director Barbara Alving, MD, is expected to serve as the acting director immediately following Dr. Lenfant's departure.

MEDICAL NEWS

HHS Releases Special Medicaid Funding

July 9, 2003

Secretary of Health and Human Services Tommy G. Thompson has announced the availability of new Federal dollars to state Medicaid programs to help states avoid further cuts in Medicaid benefits in response to budget constraints. The one-time increase was enacted as part of the Jobs and Growth Tax Relief Reconciliation Act signed into law by President Bush on May 28, 2003.

Under the new law, states will receive an increase in the amount of Medicaid matching funds from the Federal government for five calendar quarters, beginning April 1, 2003 (the current quarter) and ending June 30, 2004. The increase in the Federal share is available for all eligible expenditures and will be 2.95 percentage points over the normal Federal share amount. It is estimated that the provision will bring \$10 billion in new funding to the states.

"We have acted quickly to help states in making these special funds available to protect Medicaid benefits," Secretary Thompson said. "But we must realize that this is a short-term

approach associated with current economic conditions in the states — it does not make the reforms that are needed to protect the future healthcare of those in need. This is a bridge over a billion-dollar problem, but it still doesn't prepare us for the trillion-dollar challenges that lie ahead."

Total federal spending for Medicaid over the next ten years is estimated at \$2.6 trillion. Combined federal and state spending on Medicaid in this period is estimated at \$4.6 trillion. A letter describing the method CMS will use to determine the exact increase in each state's federal share, beginning with the current quarter, is available at <http://cms.hhs.gov/states/letters>.

Report Indicates AIDS Death Rate in the U.S. Could be Reduced by 50% with Passage and Implementation of the Early Treatment for HIV Act

July 11, 2003

A study commissioned by the Treatment Access Expansion Project (TAEP), a collaborative project of the HIV/AIDS community, health care providers and the pharmaceutical industry, and conducted by PricewaterhouseCoopers (PwC), indicates that providing early intervention healthcare access under the Early Treatment for HIV Act (ETHA) could, over a 10 year period, reduce the U.S. death rate of people with HIV on Medicaid by 50%. "The study shows that the lives of people living with HIV are in the hands of our Congress and the President," asserts Robert Greenwald, TAEP Project Director. He adds, "New HIV/AIDS treatments greatly improve health outcomes for people living with this disease. However, without access to early intervention healthcare, these advances remain out of reach for thousands of poor and low-income pre-disabled persons living with HIV. In addition to the global effort, the Administration and Congress must promote an equally aggressive domestic HIV treatment access agenda."

Under current rules, individuals with HIV-disease must become disabled by AIDS before they can receive access to Medicaid. Yet, earlier access could have prevented them from becoming so ill in the first place. Modeled after the highly successful "Breast and Cervical Cancer Prevention and Treatment Act of 2000," ETHA gives states the option of amending their Medicaid rules to provide early intervention healthcare to pre-disabled people with HIV.

The study found that providing early intervention care through ETHA significantly delays the progression of HIV disease, increases the life expectancy of HIV positive individuals and is highly cost-effective. Specifically, the study results indicate that over 10 years, the provisions of ETHA would reduce the death rate for persons living with HIV on Medicaid by 50%, that disease progression would be significantly slowed and health outcomes improved, and that Medicaid offsets alone would reduce gross Medicaid costs by approximately 70%.

ETHA (Senate 847) was introduced in the 108th Congress by Senators Gordon Smith (R-OR), Hillary Clinton (D-NY) and eight other original co-sponsors. While not yet filed in the House this session, the lead co-sponsors are Representatives Nancy Pelosi (D-CA) and James Leach (R-IA).

The full text of the report on the study is available at <http://www.taepusa.org>.

Women's Bleeding Disorders Will Again Be A Major Focus Area at NHF's Annual Meeting

August 19, 2003

Project Red Flag: real talk about women's bleeding disorders

(PRF) is NHF's special campaign for women and girls, developed in cooperation with the CDC and through generous funding from Aventis-Behring. NHF's 55th Annual Meeting will feature several PRF sessions/ events of particular interest to women and girls with bleeding disorders. These include separate "Ask the Expert" sessions for carriers and women with von Willebrand disease.

In attendance will be noted obstetricians/gynecologists Doctors Andra James and Andrea Lukes. A PRF reception and update will be hosted by NHF's Women with Bleeding Disorders Task Force, with the participation of our PRF partners, CDC and Aventis Behring.

For full Annual Meeting information, visit www.hemophilia.org

Planning and Registration for NHF's 55th Annual Meeting in Salt Lake City in High Gear

August 21, 2003

Registration for NHF's 55th Annual Meeting, to be held November 6-8, 2003, in Salt Lake City, Utah, is proceeding at a rapid pace. Online early registration at www.hemophilia.org has been happening for months, and thousands of people across the country recently received complete registration materials at home, so mail registrations are now coming in on a daily basis.

The rich diversity and shared experience in the bleeding disorders community suggested the theme for NHF this year's meeting: Many Stories, One Voice.

Some highlights of this Annual Meeting include a wide array of new sessions and activities, including:

- ▶ Four provider preconferences-adding a physical therapy symposium to the Thursday preconference line-up on topics ranging from Issues of Intimacy and Sexuality, Kinesiology of Gait, Hepatitis C and HIV to Proteomics
- ▶ Welcome receptions for new families, social workers, chapters, and women with bleeding disorders
- ▶ An Opening Session with a focus on the rich, diverse stories of this community
- ▶ Ask the Expert sessions for women with bleeding disorders—both for carriers and for VWD and other bleeding disorders
- ▶ A mini-symposium on inhibitors, ports and prophylaxis
- ▶ A special rap session for families dealing with inhibitor issues
- ▶ A mini-symposium dedicated to exploring the critical national problem of obesity in the context of bleeding disorders.

The 55th Annual Meeting will also continue to offer the workshop on summer camps, and sessions on blood safety, hemophilia and bleeding disorders 101, alternative therapies, multicultural issues, social work and nursing case studies, our popular rap sessions, networking and social events and much more.

Full details and on-line registration is available at www.hemophilia.org. If you would rather register by mail and did not receive a registration book, please call the contact NHF's Meetings Department at 800-424-2634, ext. 4 or e-mail meetings@hemophilia.org.