Congress Passes New Laws Beneficial to People With Bleeding Disorders
By Jeff Cornett, RN MSN, Director of Training, Research, & Advocacy
Horizons in Hemophilia, Winter 2009

Several new laws that help people with bleeding disorders were passed by Congress in 2008. If you have questions about these laws, contact your HoG Social Worker or Jeff Cornett, HoG’s Director of Training, Research, and Advocacy.

Genetics Information Nondiscrimination Act
On May 21, 2008, the President signed into law the Genetic Information Nondiscrimination Act (GINA). This law will protect Americans against discrimination based on their genetic information when it comes to health insurance and employment. The parts of the law relating to health insurers will take effect by May 2009, and those relating to employers will take effect by November 2009. The law does not cover members of the military. In addition, the law does not cover life insurance, disability insurance and long-term care insurance.

Hemophilia of Georgia, the National Hemophilia Foundation, and other bleeding disorder organizations lobbied hard for the bill's passage. It had been debated in Congress for thirteen years and was finally passed unanimously in the Senate and in the House by a vote of 414 to 1. The federal government has a fact sheet about the new law at http://www.genome.gov/10002328.

Amendments to the Americans with Disabilities Act
On September 25, 2008, President Bush signed the ADA Amendments Act of 2008 (ADAAA). These amendments to the Americans with Disabilities Act (ADA) of 1990 take effect January 1, 2009. The Americans with Disabilities Act (ADA) prohibits discrimination and ensures equal opportunity for persons with disabilities in employment, state and local government services, public accommodations, commercial facilities, and transportation. Since the ADA was first passed, a series of Supreme Court decisions has narrowed the definition of a disability.

With the new amendments, Congress has stated that it wants the law to cover a broad range of individuals, not a narrow one. The new law makes it clear that people with bleeding disorders are protected from discrimination under the ADA. The original ADA defines a disability as one involving a physical or mental impairment that substantially limits one or more major life activities. The new law states that a major life activity includes the operation of a major bodily function, including but not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions. Circulatory functions include the ability of blood to clot normally. The federal government maintains a website with full information about the Americans with Disabilities Act at http://www.ada.gov/.

Michelle’s Law (H.R. 2851)
Last October 9 President Bush signed “Michelle’s Law” (H.R. 2851). The law was passed unanimously by Congress. This law allows some seriously ill college students to take up to 12 months medical leave from
school without the risk of being dropped from a parent's health insurance plan. The law is named after Michelle Morse, who attended college full-time in New Hampshire. After being diagnosed with colon cancer in 2004, she was forced to maintain a full class load while undergoing chemotherapy in order to remain eligible for health insurance under her parents' health care plan. She ultimately lost her battle with colon cancer and her family worked to get the insurance rules changed.

The law requires students to provide written documentation from a medical professional explaining the need for the temporary medical leave. It only applies to full-time students who are already dependents on a health plan. The law does not require insurance companies to cover any new procedures or new individuals – it just prevents them from dropping coverage. The new law takes effect October 9, 2009.