

Genetic Anti-Discrimination Bill Clears Congress

The House passed the Genetic Information Nondiscrimination Act on May 1, 2008. The act will protect Americans against discrimination based on their genetic information regarding health insurance and employment.

The Senate unanimously approved the legislation on April 24. It is anticipated that President Bush will sign the bill soon.

The long-awaited measure, which has been debated in Congress for 13 years, will pave the way for people to take full advantage of the promise of personalized medicine without fear of discrimination.

Below is a partial summary of the bill

Genetic Information Nondiscrimination Act of 2008 – Title I: Genetic Nondiscrimination in Health Insurance – (Sec. 101) Amends the Employee Retirement Income Security Act of 1974, the Public Health Service Act, and the Internal Revenue Code to prohibit a group health plan from adjusting premium or contribution amounts for a group on the basis of genetic information.

Prohibits a group health plan from requesting or requiring an individual or family member of an individual from undergoing a genetic test. Provides that such prohibition does not: (1) limit the authority of a health care professional to request an individual to undergo a genetic test; or (2) preclude a group health plan from obtaining or using the results of a genetic test in making a determination regarding payment. Requires the plan to request only the minimum amount of information necessary to accomplish the intended purpose.

Allows a group health plan to request, but not require, a participant or beneficiary to undergo a genetic test for research purposes if certain requirements are met, including: (1) the plan clearly indicates that compliance is voluntary and that noncompliance will have no effect on enrollment status or premium or contribution amounts; (2) no genetic information collected or acquired is used for underwriting purposes; and (3) the plan notifies the Secretary of Health and Human Services that it is conducting activities pursuant to this exception and includes a description of the activities.

Prohibits a group health plan from requesting, requiring, or purchasing genetic information: (1) for underwriting purposes; or (2) with respect to any individual prior to such individual's enrollment in connection with such enrollment (provides that incidentally obtains such information is not a violation). Applies such prohibitions to all group health plans, including small group health plans.

Provides that any reference to genetic information concerning an individual or family member includes genetic information of: (1) a fetus carried

by a pregnant woman; and (2) an embryo legally held by an individual or family member utilizing an assisted reproductive technology.

(Sec. 104) Amends title XVIII (Medicare) of the Social Security Act to prohibit an issuer of a Medicare supplemental policy, on the basis of genetic information, from: (1) denying or conditioning the issuance or effectiveness of the policy, including the imposition of any exclusion of benefits based on a preexisting condition; or (2) discriminating in the pricing of the policy, including the adjustment of premium rates.

Prohibits an issuer of a Medicare supplemental policy from: (1) requesting or requiring an individual or a family member to undergo a genetic test; or (2) requesting, requiring, or purchasing genetic information for underwriting purposes or for any individual prior to enrollment.

Title II: Prohibiting Employment Discrimination on the Basis of Genetic Information – (Sec. 202) Prohibits, as an unlawful employment practice, an employer, employment agency, labor organization, or joint labor-management committee from discriminating against an employee, individual, or member because of genetic information, including: (1) for an employer, by failing to hire or discharging an employee or otherwise discriminating against an employee with respect to the compensation, terms, conditions, or privileges of employment; (2) for an employment agency, by failing or refusing to refer an individual for employment; (3) for a labor organization, by excluding or expelling a member from the organization; (4) for an employment agency, labor organization, or joint labor-management committee, by causing or attempting to cause an employer to discriminate against a member in violation of this Act; or (5) for an employer, labor organization, or joint labor-management committee, by discriminating against an individual in admission to, or employment in, any program established to provide apprenticeships or other training or retraining.

This edition's update concerns legislation the committee has lobbied for during the past several sessions of Congress.

by
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Prohibits, as an unlawful employment practice, an employer, employment agency, labor organization, or joint labor-management committee from limiting, segregating, or classifying employees, individuals, or members because of genetic information in any way that would deprive or tend to deprive such individuals of employment opportunities or otherwise adversely affect their status as employees.

Prohibits, as an unlawful employment practice, an employer, employment agency, labor organization, or joint labor-management committee from requesting, requiring, or purchasing an employee's genetic information, except for certain purposes, which include where: (1) such information is requested or required to comply with certification requirements of family and medical leave laws; (2) the information involved is to be used for genetic monitoring of the biological effects of toxic substances in the workplace; and (3) the employer conducts DNA analysis for law enforcement purposes as a forensic laboratory.

(Sec. 206) Requires an employer, employment agency, labor organization, or joint labor-management committee that possesses any genetic information about an employee or member to maintain such information in separate files and treat such information as a confidential medical record.

Prohibits an employer, employment agency, labor organization, or joint labor-management committee from disclosing such genetic information, except: (1) to the employee or member upon request; (2) to an occupational or other health researcher; (3) in response to a court order; (4) to a government official investigating compliance with this Act if the information is relevant to the investigation; (5) in connection with the employee's compliance with the certification provisions of the Family and Medical Leave Act of 1993 or such requirements under state family and medical leave laws; or (6) to a public health agency.

Respite Care Legislation Update

by *Denise Dengel*

The Legislative Committee has been working with the Lifespan Respite Task Force for the past few years to have a law passed and funded that would provide our families with much needed respite care. The Lifespan Respite Task Force is a coalition of more than 170 national and state organizations. It is a working group of the National Respite Coalition, which is a coalition of national and state organizations that came together to develop and promote a national respite policy.

On Dec. 21, 2006, the president signed into law "*The Lifespan Respite Care Act of 2006.*"

Although The Lifespan Respite Care Act was signed into law in 2006, it was not funded.

The National MPS Society as well as 59 other national organizations sent a letter to both the House and Senate Appropriations Subcommittees in support of full funding of \$53.3 million for Lifespan Respite in the FY09 Labor, HHS and Education Appropriations bill. The Senate passed an amendment by unanimous consent to the Senate Budget Resolution reserving \$53 million for Lifespan Respite in the budget.

The Legislative Committee will continue to work on this important law being funded so our families can receive the quality respite care they deserve.

Summary of the Lifespan Respite Act (PL109-442):

Use of Funds:

The Act authorizes competitive grants to Aging and Disability Resource Centers in collaboration with a public or private non-profit state respite coalition or organization to make quality respite available and accessible to family caregivers regardless of age or disability. The law allows grantees to identify, coordinate and build on federal, state and local respite resources and funding streams, and would help support, expand and streamline planned and emergency respite, provider recruitment and training, and caregiver training. Grantees will have the option of using funds for training programs for family caregivers in making informed decisions about respite services; for other services essential to the provision of respite; and for training and education for new caregivers.

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What is a Lifespan Respite Program?

A lifespan respite program provides a coordinated system of accessible, community-based respite care services for family caregivers of children and adults with special needs.

Who Can Access Lifespan Respite Programs?

Caregivers who are family members, foster parents, or other adults providing unpaid (clarified in report language) care for an adult or child with a special need may access these programs. An adult with a special need is defined broadly as a person 18 years of age or older who requires care or supervision to meet the person's basic needs, to prevent physical self-injury or injury to others, or to avoid placement in an institutional facility. A child with a special need is a person less than 18 years of age who requires care or supervision beyond that required of children generally to meet the child's basic needs or prevent physical self-injury or injury to others.

Respite Care Legislative Update:

On March 13, 2008, the Senate passed an amendment by unanimous consent to the Senate Budget Resolution reserving \$53 million for Lifespan Respite in the budget. The amendment was offered by Sen. Clinton (D-NY) and Sen. Warner (R-VA).

While this amendment does not guarantee an appropriation for the program, it is a critically important step in the process and will make it that much easier to secure the funding during the upcoming FY09 appropriations process. The budget resolution is nonbinding, but it sets important parameters that must be followed by appropriators when considering spending bills.

The House Labor/HHS/Education Appropriations Subcommittee could take action on the FY09 funding bill as soon as late May and the Senate as early as June. We will keep you posted; keep contacting your representatives and senators.

One of the goals of the National MPS Society is to increase awareness of MPS diseases. With the assistance and persistence of our members, we are making great strides. Don't forget to let the MPS Society know when you are featured in a media story!

The *Cherokee Tribune*, Canton, GA, ran an article featuring 18-year-old Erin Peters (MPS III), who recently was given a new hot tub by ThermoSpa to help with her water therapy.
