

Genetic Discrimination

ACTION NEEDED:

Congress needs to approach making changes to the genetic discrimination provisions contained Health Insurance Portability and Accountability Act of 1996 (HIPAA) with caution. Any new legislation needs to balance the need to protect consumers with the need to keep health insurance affordable and accessible. Provisions that would prevent normal underwriting procedures or expose health insurers or employers to unlimited liability could result in significant increases to health insurance premiums.

BACKGROUND:

Federal law under HIPAA already provides important protections to prohibit discrimination against individual members of a group health insurance plan on the basis of current health status or some future predisposition to a particular disease based on genetic testing.

HIPAA prohibits denial of benefits or increases in premium to individual members of a group health plan due to health status. In addition, group health plans of all sizes are guaranteed the right to renew policies, and employees may move between group health plans with full credit towards preexisting conditions limitations that have already been satisfied without regard to health status, including any information obtained through genetic testing.

NAHU discourages any activity by insurance carriers that would increase premiums or terminate coverage of an individual employee of a group health plan due to health status.

The issue surrounding prohibition of discrimination by employers or health insurance carriers due to genetic information has evolved over the past few years. Prohibition of the use of genetic information in the health insurance underwriting process has resulted in a variety of opinions as to how genetic information and genetic tests should be defined.

Some groups have broadened the definition to include items that go beyond what is normally considered a genetic test. Using a broader definition could disrupt and prevent normal underwriting procedures, resulting in unaffordable health insurance premiums for employers and consumers alike.

The first issue regarding the definition of genetic information relates to when information should be considered genetic information. HIPAA prohibits discrimination by any individual within a group based on health status, including genetic information, in the absence of a diagnosis. Genetic information when no diagnosis or symptoms of illness is present is sometimes called "predictive" genetic information.

Some pending legislation removes all reference to whether or not testing is done in connection with a diagnosis or symptoms and simply protects all genetic information. This in effect goes far beyond the HIPAA standard and would prevent genetic information from being used in health insurance underwriting or by employers even when a diagnosis of illness is otherwise present. NAHU believes that the prohibition on the use

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of genetic information should be clearly limited to genetic information that is not associated with an existing diagnosis or symptoms.

Because HIPAA did not adequately define what "genetic information" is, NAHU feels it is important to clearly specify what should be included in that term.

NAHU supports a definition of genetic information that is limited to DNA and related gene testing done for the purpose of predicting risk of disease in asymptomatic or undiagnosed individuals, and which clearly excludes such items as age, gender and information from physical exams and lab work, including items like cholesterol tests, performed to detect symptoms, clinical signs or a diagnosis of disease.

Some genetic-discrimination proposals would make insurance carriers, health plans and employers vulnerable to unlimited and frivolous lawsuits. These bills would prohibit employers from using genetic information in hiring and firing but use such a broad definition of genetic information that employers that perform multiple human resources functions (e.g., hiring/firing and health benefits administration) could be severely impacted as they move from one functional role to another.

NAHU is concerned that small employers could be particularly vulnerable. A casual remark made about someone's mother's health at a water cooler, for instance, could place the employer in an unfavorable position of having knowledge of "family medical history," which may be considered genetic information under some legislation.

The possibility of virtually unlimited liability could prove to be a financial hardship for many employers and dampen their enthusiasm to offer benefits.

NAHU recognizes the beneficial uses of genetic testing to fight disease and its potential utility in the general practice of medicine. We look forward to working with the medical community, Congress and the states to develop ethical guidelines for the appropriate use of genetic information that are in the best interest of the American people.