



Position Statement on Genetic Nondiscrimination Revised – March 2007

AHIMA's Position

Protections against genetic discrimination should extend to all Americans in all circumstances including employment and insurance.

Congress should pass and the President should sign legislation as soon as possible to prohibit discrimination based upon genetic information.

Genetic information nondiscrimination legislation should apply to all public, private or government regulated insurance programs. Insurers should be prohibited from denying coverage or instituting higher premiums based upon genetic information or a genetic predisposition towards future disease. Further, insurers should be prohibited from requesting or requiring individuals to take genetic tests and should be prevented from acquiring predictive genetic information or genetic services prior to an individual's enrollment.

The legislation should also be applicable to employers, employment agencies, training programs, and organized labor organizations. Employers should be prohibited from using an individual's genetic information to make any employment decisions and should be prohibited from collecting genetic information. Employers should be permitted to monitor the effects of hazardous workplace exposures through genetic testing and any genetic information held by employers should be confidentially maintained and disclosed only to the employee. Any illegal disclosures must be prosecuted under the Health Insurance Portability and Accountability Act (HIPAA) privacy rule.

Current Situation

Scientists at the National Institutes of Health (NIH) have completed one of the world's most intriguing puzzles, the mapping of the human genome. Understanding the human genetic code may provide a cure for cancer, Hansen's disease, or countless other diseases and genetic disorders. It also will enable the creation of pharmaceuticals genetically tailored for individual patients to treat or prevent disease.

The personalized medicine approach will enable the inclusion and use of genetic information to help tailor care plans to halt or alleviate a wide-range of potential diseases or afflictions for individuals who are genetically susceptible to them. Additionally, in the near future, through pharmacogenetics, prescriptions, and medical claims, genetic information will be an integral part of our health information and easily accessible by employers, insurers, and others. However, Americans fear their genetic information could be used against them, which prevents them from undergoing genetic tests and thus inhibits preventative personalized medicine approaches, treatment and important research.

Today, some protections for genetic information exist. Genetic information falls under the HIPAA privacy rule as protected health information. HIPAA prohibits excluding an individual from group coverage because of past or present problems, including genetic information. Specifically, in the absence of a diagnosis of a condition, it prohibits genetic information from being considered a preexisting condition.¹ Further, a majority of states have enacted laws dealing specifically with use of genetic information by employers and health insurance providers.

Over the years, support for genetic nondiscrimination legislation has been strong. In February 2000, President Clinton signed Executive Order 13145 on February 8, 2000, prohibiting federal departments or agencies from requiring genetic test results from applicants or current employees. President Bush continued this Executive Order and has expressed support for the genetic nondiscrimination proposals introduced in Congress. Recognizing that federal legislation, is necessary to protect all citizens against negative decisions made by employers, insurers and others based upon the *potential* that an individual may, at some point in the future, develop a disease or condition, the U.S. Senate unanimously (98-0) passed the Genetic Information Non-discrimination Act of 2005 (S 306) in March 2005.

In 2004 President Bush called for an electronic health record by 2014. The President, the Secretary of Health and Human Services, the Office of the National Coordinator for Health Information Technology, the American Health Information Community and the healthcare marketplace have taken bold steps to meet the President's goal to establish standards for electronic health records, personal health records and health information exchange networks that will meet many of our 21st century healthcare needs. While surveys have shown that these goals have public support, they also report the public's fear of misuse of their healthcare information. Passage of genetic nondiscrimination legislation will increase public trust in the electronic health record and network envisioned by the President.

Genetic Nondiscrimination Will Be Achieved When:

- Congress passes and the President signs legislation providing protections against and penalties for genetic nondiscrimination.
- Our nation has uniform protections against genetic discrimination.
- Genetic information is only used for legitimate purposes, and only as provided by law.
- Individuals and families have the confidence to take genetic tests to discover any predispositions to future diseases.
- Future medical discoveries are made possible through the use of genetic information for research.
- People trust electronic health records and the networks that permit appropriate exchange of individual health information.

AHIMA

AHIMA is the premier association of health information management (HIM) professionals. AHIMA's 51,000 members are dedicated to the effective management of personal health information needed to deliver quality healthcare to the public. Founded in 1928 to improve the quality of medical records, AHIMA is committed to advancing the HIM profession in an increasingly electronic and global environment through leadership in advocacy, education, certification, and lifelong learning.

ⁱ Health Insurance Portability and Accountability Act, PL 104-191, 701, 11-STAT, 1936 (1996).