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# ESTABLISHING FEDERAL PROTECTIONS AGAINST GENETIC DISCRIMINATION

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American College of Physicians  
Policy Monograph  
2008



# ESTABLISHING FEDERAL PROTECTIONS AGAINST GENETIC DISCRIMINATION

A Policy Monograph of the  
American College of Physicians

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## Executive Summary

This policy monograph highlights the need for federal protections against genetic discrimination in employment and insurance decisions in the United States and issues the American College of Physicians' new policy positions outlining what ACP believes should be included in the federal protections. The monograph contains the following six policy positions:

**Position 1: Insurance providers should be prohibited from using an individual's genetic information to deny or limit health coverage or establish eligibility, enrollment, or premium contribution requirements.**

**Position 2: Insurance providers should be prohibited from establishing differential premiums based on an individual's genetic information or request for genetic screening.**

**Position 3: Employers should be prohibited from using an individual's genetic information in employment decisions, such as hiring, promoting, or terminating an employee or establishing the terms, conditions, and benefits of employment.**

**Position 4: Insurers and employers should be prohibited from requiring individuals and families to undergo genetic testing.**

**Position 5: Insurers and employers should be prohibited from collecting and/or disclosing an individual or family's genetic information. Written and informed consent should be required for each disclosure of genetic information and should include to whom the disclosure is made.**

**Position 6: Congress should establish comprehensive and uniform federal protection against genetic discrimination that closes the gaps in protection due to varying state laws. Federal protection should also cover ERISA health plans.**

## Introduction

The United States is moving into an era of genetics and genomics—as evidenced by the ever-increasing number of clinically available genetic tests and advances in pharmacogenetics. As a result of this and growing public fears about genetic disclosure and discrimination, Congress continues to move closer to passing federal legislation that protects the use of genetic information in employment and insurance coverage decisions. This policy monograph provides an overview of genetic discrimination and the federal legislation currently under consideration to protect against it, in addition to outlining new policy positions from the American College of Physicians (ACP).

## Genetic Discrimination

Genetic discrimination refers to the use of genetic information to discriminate against an individual in decisions concerning employment and insurability. As the availability of genetic tests increases, so does fear in the general public that employers and health insurers may use an individual's genetic test results to limit or deny access to employment or health insurance.

A March 2007 survey conducted by the Johns Hopkins Genetics and Public Policy Center found that although most people trust their physicians and genetic researchers with access to their genetic information (86% and 66%, respectively), they do not trust health insurers and employers (25% and 17%, respectively) not to misuse their genetic information—either by disclosing the information or discriminating against them—should they have access to it (1). The general public largely believes that genetic information should be protected private information. Advocates for federal protections against genetic discrimination, including the Secretary's Advisory Committee on Genetics, Health, and Society and the National Genome Institute, note that “without comprehensive legal protections, the public fears genetic discrimination, and that fear has negative effects on both medical research and clinical care” (1). *Faces of Genetic Discrimination: How Genetic Discrimination Affects Real People*, a report by the National Partnership for Women and Families on behalf of the Coalition for Genetic Fairness, documents examples of how fears of genetic discrimination have negatively impacted patient health care and financial well-being, public health, and scientific advancements. Examples include shielding genetic information from health care providers, refusing genetic testing, or undergoing testing using an alias. Such actions could potentially harm patients, as they “lose the benefit of more complete medical histories which could have enabled their health providers to better diagnose, treat or prevent the onset of illness” (2). Individual decisions to forgo genetic testing or withhold genetic information due to fears of genetic discrimination deprive Americans of the “potential public health benefit of increased awareness of rare genetic disorders” and limit our ability to comprehensively implement preventive and therapeutic care programs. Additionally, fears of genetic discrimination have limited individuals' participation in medical research studies, thus negatively impacting advances in medical and scientific knowledge and development of new technologies (2).

## The Need for Federal Protections against Genetic Discrimination

During the enactment of the Health Insurance Portability and Accountability Act (HIPAA) of 1996, Congress specifically noted genetic information as “protected health information,” in addition to prohibiting insurers from considering a genetic risk factor for disease as a preexisting condition. Similarly, during the development of the privacy regulations required under HIPAA, the Department of Health and Human Services clearly noted that access to and disclosure of genetic health information are protected. It is often thought that HIPAA regulations provide sufficient federal protection against genetic discrimination; however, that is not the case. HIPAA regulations do not prohibit use of genetic information as a basis for charging a covered group larger premiums for health insurance if one member of that group tests positive for a genetic disorder; limit the collection of genetic information by insurers; prohibit insurers from requiring an individual to undergo a genetic test; limit the disclosure of genetic information by insurers; or prohibit the use of genetic information for underwriting in the individual market.<sup>1</sup>

A May 2005 report commissioned by the Department of Health and Human Services’ Secretary’s Advisory Committee on Genetics, Health and Society (SACGHS) found that current federal statutes and constitutional protections—including HIPAA, the Americans with Disabilities Act, Title VI of the Civil Rights Act, and the Right to Privacy and Fourth Amendment protections—that address genetic information in employment and health insurance are “incomplete in both the scope and depth of [their] protections” (3). Current federal protections against discrimination in health insurance do not cover individual insurance policies. Additionally, an insurer of a group may request, require, or otherwise obtain an individual’s genetic information as a condition of coverage and may charge all members of the group higher premiums based on the genetic information obtained.

A review of state genetic nondiscrimination laws reveals a largely inconsistent framework—the levels of protections provided to individuals and groups vary greatly from state to state. As of May 2007, 35 states have enacted laws prohibiting genetic discrimination in employment; and 47 have enacted laws prohibiting it in health insurance. Currently there is no body of case law that protects an individual from genetic discrimination at the federal or state levels. Further, although insurance companies have portability protections across states, these protections do not transfer for the insured. As such, if an individual moves from one state that provides protection against genetic discrimination in health insurance to another state without such protections, he/she is no longer protected, even if the individual remains with the same insurance company.

In the states that protect against genetic discrimination, self-insured companies are generally exempt from those protections under the Employee Retirement Income Security Act of 1974 (ERISA); however, they are subject to federal regulations. To fully protect all Americans from genetic discrimination, any federal legislation should specifically cover ERISA health plans.

The Genetic Information Nondiscrimination Act (S.358/H.R.493) (GINA) would prohibit health insurers from using genetic information to set eligibility, premium, and/or contribution standards; prohibit insurers from requesting or requiring a genetic test; prohibit employers from using genetic information in making employment decisions, such as hiring, firing, and promoting; and pro-

<sup>1</sup> Note: HIPAA does however prohibit insurers from using genetic information to charge differing premiums to individuals within a coverage group.

hibit employers from requesting, requiring, or purchasing genetic information about an employee or an employee's family member (1). On April 25, 2007, the House of Representatives finally passed GINA by a vote of 420-3. As of November 1, 2007, GINA is awaiting a vote in the Senate, which previously unanimously passed the legislation in both 2003 and 2005. President Bush has indicated his willingness to sign GINA if Congress finally passes it (4). Dr. Kathy Hudson, executive director of the Genetics and Public Policy Center, has stated that enactment of GINA would "substantially enhance the current limited protections against the use of genetic information in health insurance and the workplace" (1).

Groups in support of GINA include the Society for General Internal Medicine, the National Human Genome Research Institute, the American Academy of Family Physicians, the American Academy of Pediatrics, the American Health Information Management Association, and the Association of American Medical Colleges (5). America's Health Insurance Plans (AHIP) does not oppose GINA and has publicly noted its agreement with the intent of the bill (6). The ERIC Industry Committee (ERIC) and Blue Cross Blue Shield Association do not note support or opposition to the GINA on their policy/advocacy Web pages.

## ACP Policy Positions

In the *Ethics Manual, 5th Edition*, ACP issued its positions on the individual physician's roles and responsibilities in genetic testing and counseling. ACP's new policy positions, outlined below, address what should be included in federal protections against the use of genetic information in employment decisions or access to and level of coverage of health insurance and establishment of premiums.

**Position 1: Insurance providers should be prohibited from using an individual's genetic information to deny or limit health coverage or establish eligibility, enrollment, or premium contribution requirements.**

**Position 2: Insurance providers should be prohibited from establishing differential premiums based on an individual's genetic information or request for genetic screening.**

**Position 3: Employers should be prohibited from using an individual's genetic information in employment decisions, such as hiring, promoting, or terminating an employee or establishing the terms, conditions, and benefits of employment.**

**Position 4: Insurers and employers should be prohibited from requiring individuals and families to undergo genetic testing.**

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**Position 6: Congress should establish comprehensive and uniform federal protection against genetic discrimination that closes the gaps in protection due to varying state laws. Federal protection should also cover ERISA health plans.**



## Appendix

The commonly accepted definition of genetic information, as outlined in the Genetic Information Nondiscrimination Act (S.358/H.R.493), is:

### **Genetic Information**

- (A) **IN GENERAL:** The term *genetic information* means, with respect to any individual, information about:
- (i) Such individual's genetic tests
  - (ii) The genetic tests of family members of such individual
  - (iii) Subject to subparagraph (D), the manifestation of a disease or disorder in family members of such individual.
- (B) **INCLUSION OF GENETIC SERVICES:** Inclusion of genetic services includes, with respect to any individual, any request for, or receipt of, genetic services (including genetic services received pursuant to participation in clinical research) by such individual or any family member of such individual.
- (C) **EXCLUSIONS:** Inclusion of genetic information shall not include information about the sex or age of any individual.
- (D) **APPLICATION TO FAMILY MEMBERS COVERED UNDER SAME PLAN:** Information described in clause (iii) of subparagraph (A) shall not be treated as genetic information to the extent that such information is taken into account only with respect to the individual in which such disease or disorder is manifested and not as genetic information with respect to any other individual.

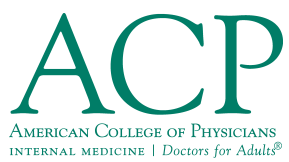
### **Genetic Test**

- (A) **IN GENERAL:** The term *genetic test* means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes.
- (B) **EXCEPTIONS:** The term genetic test does not mean:
- (i) An analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes
  - (ii) An analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved.

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