

Laws Relevant to Genetic Discrimination

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This Fact Sheet summarizes the major U.S. federal and state laws relevant to genetic discrimination in insurance and employment. Be aware that laws (especially at the state level) are frequently amended or repealed, and new laws are periodically enacted. Discrimination risks and available legal protections can also change if people change jobs or move to different states. ***This Fact Sheet should not be relied on for legal advice. Legal counsel should be consulted for advice in specific situation and for a complete analysis of the relevant laws.***

Laws Relating to Insurance

Under the Health Insurance Portability and Accountability Act (HIPAA), which applies to all employers with 2 or more employees, genetic information cannot be considered a pre-existing condition, in the absence of a diagnosis of a genetic condition. This means that:

- Patients who are covered by group health insurance plans cannot be excluded from group coverage based on pre-symptomatic genetic test results.
- Participants who are covered by group health insurance plans cannot be refused coverage for a particular condition based on pre-symptomatic genetic test results.

HIPAA operates as a *minimum standard* and does *not* preempt state laws that provide equal or greater protection.

Patients who are covered under government health programs (e.g., Medicare, Medicaid, military) receive additional protection under federal law. These programs must accept everyone who is eligible.

Numberous states (39 as of 2001) have enacted laws that specifically address genetic information and health insurance. In these states, additional protections beyond those available under federal law may be available, including protection from raising premiums. However, these laws vary considerably from state to state. The following web site has a detailed, periodically updated, listing and description of all state laws regarding genetic discrimination and insurance:
http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/insure.htm

North Carolina law specifically prohibits health insurers from using genetic information to deny or cancel coverage or to raise rates for people who have no symptoms.

No federal law specifically addresses the issue of genetic discrimination in life or disability insurance. North Carolina prohibits life insurance discrimination for carriers of sickle cell or

hemoglobin C, but not with respect to any other genetic conditions.

Laws Relating to Employment

Under the Americans with Disabilities Act (ADA), which applies to employers with *15 or more employees*, employers are prohibited from discriminating against individuals with disabilities. However, the extent to which the ADA provides protection against *genetic* discrimination in employment remains unclear in several respects. For example:

- The ADA likely *would* protect someone who now has cancer and is symptomatic.
- It is *unclear* whether the ADA would protect someone who previously had cancer, or someone whose genes predispose them to cancer. Most experts believe the ADA likely *would* apply in these situations, but this has not yet been tested in the courts.

Assuming that the ADA *does* apply to individuals who are either at risk for a genetic disorder, it protects them *only* from *discrimination*. It does *not* necessarily, at all stages, protect them from having to *disclose* their genetic status to an employer (e.g., by being asked to sign a general medical release, or by responding directly to questions about health history). Examples:

- At the *preemployment stage*, while an employer is assessing an applicant's qualifications, the employer *may not* ask anything about the applicant's genetic status (or require any general release of records). The only permissible inquiries at this time concern whether the applicant can perform, with or without reasonable accommodation, essential job functions.
- At the *preplacement stage* (after a conditional offer of employment has been made), an employer *may* require the prospective employee to consent to the release of all his/her medical records (including any genetic information in those records) as a valid condition of employment. However, the employer *may not withdraw* a conditional offer of employment based on his/her genetic status unless the employer can show that the individual is unable, even with reasonable accommodation, to perform essential job functions.¹
- At the *postplacement stage* (i.e., for current employees), an employer *may not* obtain the employee's medical records (including any genetic information in those records) without the employee's consent.

¹ As a practical matter, however, an individual in this situation will probably not know the reason for the withdrawal of a conditional offer of employment unless he or she files a complaint and obtains the information during the discovery phase of a lawsuit. Also, while the ADA prohibits employment discrimination in all aspects of employment (not just in hiring), an employer who learns of an individual's genetic status during the preplacement period may be in a position to discriminate in less obvious ways (such as in deciding future job assignments and promotions or deciding what types of benefits to include in a group health benefit package).

The ADA operates as a *minimum standard* and does *not* preempt state laws that afford equal or greater protection.

State laws analogous to the ADA that prohibit discrimination in employment based on disability have been enacted in almost every state. Some of these state laws, unlike the ADA, cover employers with fewer than 15 employees.

Federal employees receive additional protection. An Executive Order signed by President Clinton in February, 2000 prohibits federal departments and agencies from using genetic information in any employment decision. It also prohibits them (except in limited circumstances) from requesting, requiring, collecting, or purchasing genetic information, or from requesting or requiring genetic test results from applicants or current employees without their consent.

Many states (37 as of 2001) have laws concerning genetic information and employment. In these states, additional protections beyond those available under the ADA (or its state law equivalent) may be available. These laws vary considerably from state to state, however. Some prohibit *both* genetic discrimination and access by employers to genetic information, some refer only to discrimination, and some refer only to access. The following web site has a detailed, periodically-updated, listing and description of all state laws regarding genetic discrimination and employment:

http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/workplace.htm

North Carolina law prohibits employers from refusing employment based on genetic information or based on having obtained genetic services.