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Genetic Information Privacy

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❖ **Introduction**

Scientists have identified [genetic markers](#) for a variety of chronic health conditions. As of January 2007, there were more than 15,500 recognized [genetic disorders](#), affecting 13 million Americans. [1]

The passage of GINA, the [Genetic Information Nondiscrimination Act of 2008](#), took more than a dozen years. President G. W. Bush signed H.R. 493 (110th Congress) into law on May 21, 2008. GINA has applied to employers with 15 or more employees since November 21, 2009.

It applied to health insurance companies and group health plans as of May 21, 2010 or before. [2] One purpose of the legislation was to prevent unreasonable fears and prejudices from influencing decisions involving health care insurance coverage or employment.

GINA defines a genetic test as an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detect genotypes, mutations, or chromosomal changes. But it also includes information about a disease or disorder of an employee's family members, e.g., a [*family medical history*](#).

Much has been and will be written on the anti-discrimination provisions of GINA. This article principally focuses on the privacy aspects of the law.

❖ **Employer prohibitions on acquisition**

After applicants are given a [*conditional job offer*](#), they may be required to submit to medical and psychological exams. However, employers no longer are permitted to collect any genetic information, including family medical histories, from pre- or post-offer candidates.

GINA prohibits employers from *intentionally* acquiring genetic information, including a [*family medical history*](#). If a supervisor, engaged in a normal conversation, inadvertently learns from a subordinate that a coworker's family member has a serious condition or illness, there is no violation of law, provided that management does not later base an employment decision on that information. This is called the "water cooler" exception.

An employee who seeks paid or unpaid medical leave to care for a family member may be asked for specific medical documentation, but excluding a family medical history.

A worker who makes a request for a reasonable accommodation of a disability covered by the [*ADA*](#) or the [*Rehabilitation Act*](#) may be asked for relevant medical information, except for genetic information or family medical histories.

An employee lawfully may be required to furnish medical information or documentation if he or she is the subject of a *disciplinary investigation* relating to:

- (1) a possible misuse of sick time;
- (2) a dubious statement contained in a request for family or medical leave; or
- (3) a challenged work-related accommodation request.

In such cases, investigators may not ask for family medical histories.

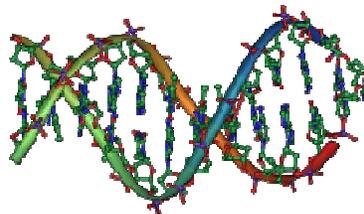
❖ Employer prohibitions on disclosure

GINA prohibits an employer, employment agency, labor organization, or joint labor-management committee from disclosing genetic information or family medical histories, 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 the 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](#) and [amendments](#) or requirements under a state's family and medical leave laws; or
- (6) to a public health agency.

❖ Records management

Employers must keep genetic, medical and health records separate from general personnel records. Typically, disciplinary investigation files also are segregated from general personnel records.



Genome

An entry in a personnel record might state that a disability accommodation or a FMLA request was approved or denied, but the supporting information should be kept in the employee's medical file.

Disciplinary actions, if any, also may be noted in a personnel record, but the documentation should be kept in a separate internal investigations dossier. This is not a GINA requirement; it is a widely-recommended practice. [3]

❖ Exclusions

Not all scientific tests implicate GINA. The law excludes tests that do not detect genotypes, mutations, or chromosomal changes. Examples include complete blood and cholesterol counts, liver enzyme tests, and analyses of proteins or metabolites that are directly related to a manifested disease, disorder, or a pathological condition.

GINA's health coverage non-discrimination protections do not apply to life, disability or long-term care insurance. Tests for alcohol or drug abuse also are excluded.

Although collective bargaining agreements sometimes waive Fourth Amendment protections of the members of a certified unit, [4] it is unlikely that a union can lawfully agree with management to waive the protections and rights granted workers in GINA. Title II specifically prohibits discrimination by unions, as well as employment agencies and training programs.

❖ Fitness for duty evaluations

Regrettably, a few police and correctional officers have feloniously killed family members, superiors, coworkers or have killed themselves. [5]

Whether a FFDE is medical or psychological, it has been common for physicians and psychologists to obtain a family medical history. Applicable EEOC regulations state: [6]

“Employers will likewise be prohibited from obtaining this type of information through any type of medical examination required of employees for the purpose of determining continuing fitness for duty.”

The regulations go on to state:

“However, Title II of GINA does not apply to information obtained by a health care professional in the course of a medical examination, diagnosis, or treatment *unrelated to a determination of fitness for duty*, except to the extent the information is obtained as part of an employer-provided voluntary wellness program.” (Italics added).

Mental health professionals sometimes compel an employee, who has been ordered to participate in a FFDE, to sign a “waiver of privacy.” At most, an unenforceable waiver is only a psychological barrier against expensive litigation and a dubious outcome.

❖ Remedies

The Departments of Labor, Health & Human Services and the Treasury have responsibility for issuing regulations for Title I of GINA, which addresses the use of genetic information in health insurance. The EEOC enforces Title II of GINA, dealing with genetic discrimination in employment.

The private enforcement mechanisms and remedies available to employees and under Title VII of the [Civil Rights Act of 1964](#) apply to GINA. [42 U.S. Code §1981a](#) also applies and limits the recovery of compensatory damages for future pecuniary losses, emotional injury, and pain and suffering. Punitive damages are not available in actions against the federal government, or against state or local government employers.

“So, sue me. What are your damages?” There are many laws that no one bothers to enforce because the cost of litigation exceeds the results obtained. However, Congress included an incentive for GINA plaintiffs. Prevailing plaintiffs are entitled to an award of attorney’s fees under [42 U.S. Code §1988](#). Aside from any personal outrage, litigants are vindicating their civil rights. [7]

GINA creates a “firewall” between Title I (health insurance) and Title II (employment) to prevent claimants from “double-barreling” – simultaneously suing under both provisions in order to aggregate the benefits of separate remedies.

- Because GINA was predicated on the [Commerce Clause](#), some lawyers have questioned whether the [11th Amendment](#) bars the inclusion of state governments as covered employers. There are an estimated five million state employees.

❖ References: *(chronological)*

Notes:

1. [Extension of Remarks of Rep. Louise Slaughter](#), Congressional Record for Jan. 16, 2007, p. E120.
2. [Public Law 110-233; 122 Stat. 881-922; 42 U.S. Code §2000ff](#). It amended and/or affected the *Fair Labor Standards Act of 1938*; the *Civil Rights Act of 1964* (EEOC and remedies); the *Employee Retirement Income Security Act of 1974*; the *Government Employee Rights Act of 1991*; the *Internal Revenue Code of 1986*; the *Social Security*

Act of 1965; the Health Insurance Portability and Accountability Act of 1996; and the Public Health Service Act of 1944.

3. See, [Law Enforcement Administrative Investigations](#) (2nd edit.) by Lou Reiter, §14.1, “Files to be maintained by IAU. Completed administrative investigations shall be maintained only in secured files.”
4. Some courts have held that a union can waive the Fourth Amendment rights of its members, and consent to suspicionless drug testing of public employees. Almost all courts and state public employment relations boards and commissions have found that drug screen procedures are a mandatory subject of bargaining.
5. [Bonsignore v. City of N.Y.](#), 521 F.Supp. 394 (S.D.N.Y. 1981), aff’d 683 F.2d 635 (2d Cir. 1982); [Spades v. City of Walnut Ridge](#), #98-4119, 186 F.3d 897 (8th Cir. 1999). Also see [Suicide and Public Safety Officers: Disciplinary, Medical and Compensation Issues](#), 2007 (5) AELE Mo. L. J. 201.
6. [EEOC Proposed Rule: Regulations Under the Genetic Information Nondiscrimination Act of 2008](#), Section 1635.8, 74 (39) Federal Register 9056-9071 (Mar. 2, 2009).
7. The Act provides for “Reasonable attorney’s fees, including expert fees, as provided for, and limited by, 42 U.S. Code §1988(b) and (c).”

General articles:

1. Law & Psychiatry: Genetic Discrimination in Mental Disorders: The Impact of the Genetic Information Nondiscrimination Act, Paul S. Appelbaum, M.D., 61 (4) Psychiatric Services 338-340, Amer. Psychiatric Assn. (Apr. 2010). [Abstract](#).
2. [Genetic Information Nondiscrimination Act of 2008](#): Information for Researchers and Health Care Professionals, Dept. of Health & Human Services (Apr. 2009).
3. [Guidance on the Genetic Information Nondiscrimination Act](#): Implications for Investigators and Institutional Review Boards, H&HS (Mar. 2009).
4. Genetic Information Nondiscrimination Act of 2008: The Federal Answer for Genetic Discrimination, Perry W. Payne, Jr., 5 (1) J. Health & Biomed. L. 33, Suffolk Univ. Law School (2009).
5. [European Practices of Genetic Information and Insurance](#): Lessons for the Genetic Information Nondiscrimination Act, I. Hoyweghen, 300 (3) J. Amer. Med. Assn. 326-327 (Jul 16, 2008).

6. [Keeping Pace with the Times](#): The Genetic Information Nondiscrimination Act of 2008, K. L. Hudson, 358 (25) New Eng. J. Med. 2661-2663 (Jun. 19, 2008).

Law review articles:

1. Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act, Jessica L. Roberts 63 Vanderbilt L. Rev. 439 (Mar. 2010). [Abstract](#).
2. [GINA: A Genetic Information Nondiscrimination Solution in Search of a Problem](#), Patricia Alten, 61 Fla. L. Rev. 379 (Apr. 2009).
3. New Frontiers for Genetic Privacy Law: The Genetic Information Nondiscrimination Act of 2008, Daniel Schlein, 19 Geo. Mason U. Civ. Rts. L.J. 311 (Spring, 2009).
4. [The Genetic Information Nondiscrimination Act of 2008](#): A Case Study of the Need for Better Congressional Responses to Federalism Jurisprudence, Harper Jean Tobin, 35 N. Dame J. of Legis. 113 (2009).

Web articles:

1. [Genetic Privacy: New Frontiers](#), Sheldon Krimsky, Tania Simoncelli

Legislative hearings:

1. [Protecting Workers from Genetic Discrimination](#): Hearing Before the House Comm. on Education and Labor, 110th Cong., Serial No. 110-1 (Jan. 30, 2007).

Federal regulations:

1. [Joint Agency] [Interim Final Rules Prohibiting Discrimination](#) Based on Genetic Information in Health Insurance Coverage and Group Health Plans (Internal Revenue Service, Dept. of the Treasury; Employee Benefits Security Administration, Dept. of Labor; Centers for Medicare & Medicaid Services, Dept. of Health and Human Services), 74 (193) Federal Register 51663-2138 (Oct. 7, 2009).
2. [EEOC Proposed Rule](#): Regulations Under the Genetic Information Nondiscrimination Act of 2008, 29 CFR Part 1635, 74 (39) Federal Register 9056-9071 (Mar. 2, 2009).

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