

GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008:

WHAT EMPLOYERS SHOULD KNOW
TO AVOID LIABILITY UNDER THE MORE
SUBTLE PROVISIONS OF THE ACT

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Fantastic advances are being made in connection with disease prevention and management through the use of genetic information to design more effective drug therapy with fewer side effects and to tailor medical treatment more specifically to an individual. However, people are concerned about what will happen if an employer or insurer finds out a person has a genetic predisposition towards certain diseases. GINA allows individuals to take advantage of these scientific advances without fearing that they will lose their jobs or insurance coverage if they do.

There are two separate titles to GINA. Title I deals with discrimination in the context of

health insurance. Title II (to which this article is limited) deals with discrimination in the context of employment practices. The Equal Employment Opportunity Commission issued final regulations implementing the provisions of Title II effective January 10, 2011.

GINA's Subtler Side

Many employers have heard about GINA for some time and have been aware of Title II's general prohibition against discrimination, in the employment setting, based on an individual's genetic information. Satisfied they know better than to consider genetic information when making hiring, firing or compensation decisions, such employers may believe they have nothing to worry about now that the final GINA regulations have gone into effect.

The Genetic Information

Nondiscrimination Act of 2008 (GINA) was signed into law by George W. Bush on May 21, 2008. The law, which protects against discrimination by insurers and employers based on an individual's genetic information, came about in response to growing concerns that the protections in the law weren't keeping up with the advances in the laboratory.

What employers should be aware of is that GINA reaches far beyond discrimination – it also prohibits employers from requesting, requiring or purchasing genetic information on an individual or family member. Again, many employers will be satisfied with their employment practice because they do not ask employees for “that kind” of information. However, what most employers may not be aware of is that the definition of “request” is not limited to actively soliciting genetic information from employees, but is actually broad enough to include information found during an internet search or gleaned from actively listening to lunch room or so-called “water cooler” talk. It can also include asking about an employee’s sick mom or about an employee’s pregnancy if the conversation or follow-up questions are too probing. These subtler violations of GINA are what employers need to be concerned with.

Thankfully, there are numerous exceptions to help employers avoid certain GINA violations, but knowledge of the law is important in order to understand what is required for the exceptions to apply or, more importantly, to prevent employers from obtaining genetic information in cases where there is no exception.

Finally, employers need to be aware of their obligation with respect to maintaining genetic information once they receive it. Employers must also post certain notices regarding the provisions of GINA and how to file a complaint in connection with GINA violations.

GINA Basics: To Whom Does GINA Apply and What Does She Prohibit?

GINA prohibits employers with 15 or more employees from discriminating “against an individual on the basis of the genetic information of the individual in regard to hiring, discharge, compensation, terms, conditions or privileges of employment.”¹ This same prohibition applies conceptually, though in slightly different forms, due to their differing relationship to employees, to employment agencies, labor organizations and joint labor-management committees.

Under GINA, employment agencies, labor organizations and joint labor-management

committees, together with employers and employing offices, are collectively referred to as “covered entities.”² It is important that employers realize a “covered entity” under GINA is different than a covered entity under the Health Insurance Portability and Accountability Act of 1996 (HIPAA).³ Many people are familiar with the term “covered entity” and believe it generally refers to health care providers, which it does under HIPAA, but covered entity has a different meaning under GINA. Thus, when reading the additional prohibitions below, the first question to ask is whether a business is a covered entity under GINA. If it is a covered entity, GINA will generally apply to it and its employment practices.

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In addition to the general prohibition against discrimination based on genetic information, GINA also prohibits a covered entity from requesting, requiring or purchasing genetic information of an

individual or family member of the individual...⁴ For reference in this article, these prohibitions will be collectively referred to as the Acquisition Prohibition.

As mentioned above, the Acquisition Prohibition is where most employers are likely to get into trouble, because the definition of request is so broad. "Request" includes:

- Conducting an internet search on an individual in a way that is likely to result in a covered entity obtaining genetic information;
- Actively listening to third-party conversations; or
- Searching an individual's personal effects for the purposes of obtaining genetic information; and
- Making requests for information about an individual's current health status in a way that is likely to result in a covered entity obtaining genetic information.

Genetic Information

Clearly, a key element in a GINA analysis, whether it involves alleged discrimination or violation of the Acquisition Prohibition, is whether the information used or obtained is "genetic information." If the information in question is not genetic information, there is not a GINA violation in connection with it. Genetic information includes:

- Information about the genetic tests of an individual or of the individual's family members;
- Manifestation of disease or disorder in the individual's family members (medical history);
- An individual's receipt or request for genetic services or participation by the individual or a family member in clinical research that includes genetic services; or
- Genetic information about a fetus carried by an individual or a fetus carried by her family member or any embryo held by the individual or the individual's family member using assisted reproductive technology.⁵

There are numerous exceptions to the Acquisition Prohibition, but the exceptions have fairly particular requirements that must be met in order to prevent GINA liability. These exceptions, which are described in more detail below, include:

- Inadvertent requests for genetic information;
- Acquisition of genetic information in connection with a voluntary wellness program;
- Requests for medical information in order to comply with the Family and Medical Leave Act

- of 1993 or other similar state or local family leave laws;
- Commercially or publicly available information;
 - Monitoring the biological effects of toxic substances in the work place; and
 - DNA analysis for law enforcement purposes.

Inadvertent Requests

Inadvertent requests include situations where an employer acquires genetic information from an employee in response to a lawful request for medical information, such as in connection with a request for accommodations under the Americans with Disabilities Act. When an employer requests such medical information it must direct the employee not to include genetic information in the employee's response. However, there are times when an employee provides genetic information in spite of such a directive. In these cases, the acquisition of genetic information will be considered inadvertent so long as the directive contains certain safe harbor language such as:

GINA prohibits employers and other entities covered by GINA Title II from requesting or requiring genetic information of an individual or family member of the individual, except as specifically allowed by this law. To comply with this law, we are asking that you not provide any genetic information when responding to this request for medical information. "Genetic information," as defined by GINA, includes an individual's family medical history, the results of an individual's or family member's genetic tests, the fact that an individual or an individual's family member sought or received genetic services, and genetic information of a fetus carried by an individual or an individual's family member or an embryo lawfully held by an individual or family member receiving assistive reproductive services.⁶

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If a covered entity fails to use the safe harbor language when making its request for medical information, it can still show that the acquisition of genetic information was inadvertent, if it can show the request was not “likely to result in the covered entity receiving genetic information.”⁷

The inadvertent request exception can also apply when an employer overhears a conversation between or among employees or when the employer asks an “ordinary question of concern.” However, if the employer follows up with questions that are probing in nature, such as whether other family members have the condition being discussed or whether the employee has also been tested if the subject is a family member, this exception does not apply, because “the covered entity should know these questions are likely to result in the acquisition of genetic information.”⁸

Voluntary Wellness Programs

Wellness programs are a great way to promote healthy living and reduce costs in connection with the provision of health insurance to employees, but in order for a covered entity to avoid violating the Acquisition Prohibition in connection with wellness programs, provision of genetic information in connection with participation in the program must be voluntary. “Voluntary” requires that not only is provision of genetic information not required, but that a participant cannot be penalized for failure to provide it. Financial inducements offered in connection with the program cannot be tied to provision of genetic information and if financial inducements are offered, an explanation using basic language easy for the participant to understand must make that fact clear.⁹

FMLA

If a covered entity requests a family medical history to comply with the certification provisions of the FMLA or

other state or local leave laws, there will not be a GINA violation in connection with the request for such information.¹⁰

Commercially and Publicly Available

Acquisition of genetic information from documents that are commercially and publicly available for review or purchase is not a violation of the Acquisition Prohibition provided that the documents were not on databases with restricted or limited access or where the covered entity is likely to acquire genetic information such as chat rooms of social network pages that focus on genetic issues.¹¹

Monitoring Biological Effects of Toxic Substances

A covered entity will not commit a violation of the Acquisition Prohibition if it acquires genetic

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information in connection with monitoring biological effects of toxic substances in the workplace so long as the covered entity provides notice of the monitoring and keeps the individual apprised of the results of the monitoring. This exception further requires that the monitoring be required by law and conducted in accordance therewith, or with knowing, voluntary and written authorization of the subject. The authorization must meet certain requirements as well.¹²

DNA Analysis for Law Enforcement

It is not a violation of the Acquisition Prohibition if an employer uses genetic information in connection with DNA analysis as a forensic lab or in connection with identification of remains.¹³

Requirements for Maintaining Genetic Information and Limitation on Disclosure of Genetic Information

While the foregoing exceptions set forth when the request for, requirement of or purchase of genetic information is not a violation of the Acquisition Prohibition, what a covered entity does with genetic information it has legally obtained can be a violation of other provisions of Title II.

A covered entity must keep genetic information in medical files that are separate from personnel files and treat the information as a confidential medical record.¹⁴ Genetic information that a covered entity acquires through oral communication is not required to be reduced to writing but may only be disclosed under the same circumstances as written genetic information.¹⁵

Written genetic information may only be disclosed as follows:

- To the employee or family member about whom it pertains;
- To an occupational or other health researcher, subject to certain federal research requirements;
- In response to a court order so long as the information disclosed is specifically covered by the order;
- To government officials investigating a GINA violation;
- In support of an employee's compliance with certification requirements of FMLA or other state leave laws; or
- To a federal, state or local health agency in connection with the manifestation of contagious disease that presents an imminent hazard of death or life-threatening illness.¹⁶

In connection with disclosures pursuant to a court order or to a health agency, the subject of the disclosure must be notified of the disclosure.

Doesn't HIPAA Cover This Kind of Thing?

Title II does not apply to genetic information that is considered protected health information and subject to the regulations of HIPAA.¹⁷ If an entity is covered by HIPAA, it must follow the HIPAA regulations with respect to genetic information. If an entity is a GINA-covered entity, the GINA provisions govern how it acquires, maintains and discloses genetic information.

Penalties for GINA Violations

Penalties for GINA violations include compensatory and punitive damages, as well as attorneys' fees and certain expert fees. Injunctive relief is also available, which can include reinstatement and hiring, back pay and other equitable remedies.¹⁸ ■



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1 29 C.F.R. § 1635.4 (a).

2 29 C.F.R. § 1635.2 (b).

3 The interplay of HIPAA and GINA is discussed more fully below.

4 29 C.F.R. § 1635.8 (a).

5 29 C.F.R. § 1635.3 (c).

6 29 C.F.R. § 1635.8 (b)(1)(i)(B).

7 29 C.F.R. § 1635.8 (b)(1)(i)(C).

8 29 C.F.R. § 1635.8 (b)(1)(ii)(A)-(B).

9 29 C.F.R. § 1635.8 (b)(2)(i)-(ii).

10 29 C.F.R. § 1635.8 (b)(3).

11 29 C.F.R. § 1635.8 (b)(4).

12 29 C.F.R. § 1635.8 (b)(5).

13 29 C.F.R. § 1635.8 (b)(6). This exception is specific to employers.

14 29 C.F.R. § 1635.9 (a)(1).

15 29 C.F.R. § 1635.9 (a)(3).

16 29 C.F.R. § 1635.9 (b)(1)-(6).

17 29 C.F.R. § 1635.11 (d).

18 29 C.F.R. § 1635.10 (b).