

MEMORANDUM 08-48

MAY 28, 2008

TO: HR Policy Company Representatives

FR: Jeffrey C. McGuiness
PresidentRE: **Congress Enacts Genetic Discrimination Legislation**

GINA Would Impose Restrictions on Collection of Genetic Information Even If Done in Compliance With ADA, Imposes Punitive Damages for Technical Violations

The Genetic Information Nondiscrimination Act of 2008 (H.R. 493) (GINA), passed the Senate by a vote of 95-0 on April 24, 2008 and the House by a vote of 420-1 on May 1, 2008, and was signed by President Bush on May 21, 2008. GINA is the first civil rights act of the 21st century and the first new federal nondiscrimination law since the Americans with Disabilities Act of 1990 (ADA). GINA prohibits discrimination based on genetic information as well as the use and collection of such information by private employers and insurers.

Unlike the situations leading to the enactment of previous other nondiscrimination laws, there is virtually no evidence of genetic discrimination by U.S. employers nor is that the impetus for the legislation. Instead, it is being driven by the concern that individuals will be inhibited from engaging in genetic testing for fear of discrimination. Indeed, GINA is the first nondiscrimination law to be passed in *anticipation* of employment discrimination. The enactment of GINA is preceded by some 35 state genetic antidiscrimination laws, but GINA does not preempt these laws.

The law underwent significant revisions since its initial introduction. However, it still contains a number of challenges for employers, as described in this analysis. Even technical violations could subject an employer to punitive and compensatory damages.

Most significantly, because the legislation was enacted in the absence of any history of discrimination, stakeholders and legislators have not been able to adequately anticipate all of the situations that may be covered, or arguably covered by the bill. Thus, many employers are concerned that creative interpretations by the courts and federal agencies could expand the sweep of the measure well beyond what Congress intended.

IN BRIEF

An employer who inadvertently receives genetic information about an employee would be vulnerable to a lawsuit if any adverse action were later taken against the employee, even if based on reasons unrelated to the genetic information.

Despite strong bipartisan support for the bill, evidence of widespread genetic discrimination is virtually non-existent.

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See the Genetic Nondiscrimination in Health Insurance and Employment Act (S. 358/H.R. 493) at http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=110_cong_bills&docid=f:h493ih.txt.pdf

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The Push for Genetic Discrimination Legislation

On June 26, 2000, Dr. Francis Collins, the Director of the National Human Genome Research Institute, announced a major breakthrough in medical science; namely that the “Human Genome Project” had mapped nearly all of the human genes. The hope associated with this pioneering scientific achievement is that further genetic research will lead researchers and healthcare providers to be able to better predict, treat, and cure diseases. While genetic research has been universally applauded, some health advocacy and civil rights groups expressed concern that people would be reluctant to undergo genetic testing because they would fear the results would be used to discriminate against them in employment.

One of the arguments against enacting genetic discrimination was that Equal Employment Opportunity Commission (EEOC) enforcement of the ADA negated the need for it. Indeed, in 2000, the EEOC sued Burlington Northern for allegedly engaging in genetic discrimination in violation of the ADA. The case ultimately settled without the company admitting it had engaged in illegal discrimination. If the EEOC’s view of the law was indeed correct, opponents of genetic discrimination legislation questioned whether there was a need for the bill, particularly given the lack of evidence or allegations of widespread genetic discrimination.

Even so, health advocacy and civil rights groups continued pressing for new federal protections against genetic discrimination. During the Clinton Administration, these advocates successfully persuaded President Clinton to issue Executive Order 13145 (Feb. 8, 2000) prohibiting genetic discrimination in federal sector employment. Advocates then sought to broaden this prohibition through legislation.

Early in the 110th Congress, the Genetic Information Nondiscrimination Act of 2007 (H.R. 493/S. 358), was introduced by Rep. Louise Slaughter (D-NY) and Sen. Olympia Snowe (R-ME). It easily passed the House by a vote of 420-3 on April 25, 2007. Despite widespread bipartisan support for GINA, the bill was held up in the Senate for almost a year because of the potential exposure of employers to punitive and compensatory damages based on medical disputes, employers being sued under both titles of the bill, and potential liability for violations by the third party administrator of the health insurance programs employers offered to their employees. That problem was addressed by clarifying the remedy provisions in the employment title to preclude such claims against employers.

Protection Under Existing Laws Untested Due to Absence of Widespread Genetic Discrimination

Prior to H.R. 493, federal law (excluding the Executive Order) has not explicitly targeted genetic discrimination. But at least two statutes—the Americans with Disabilities Act (ADA) and Title VII—potentially provide protection against genetic discrimination. The fact that protection under these laws is largely untested in the courts reflects the absence of widespread genetic discrimination by employers. Meanwhile, over 35 states have laws prohibiting employment discrimination based on genetic information.¹

Congress passed the ADA in 1990 to protect against discrimination in employment on the basis of disability and to provide equal access to public accommodations to persons with

disabilities. Although the law does not specifically address genetic discrimination, the EEOC took the position, in its 1995 Guidance on Disability,² that genetic discrimination is prohibited under the definition of “disability” that protects individuals who are “regarded as” having impairments that substantially limit one or more major life activities.³ Thus, an individual with no actual impairment (or no record of impairment) may still be deemed “disabled” under the ADA if an employer perceives or regards an employee as having an impairment that would substantially limit a major life activity. This provision reflects Congress’ determination that adverse employment actions based on the reaction of others to an impairment or a perceived impairment constitutes discrimination and should be prohibited the same as discrimination based on an actual disability.

The ADA also provides protections to employees that are asked to undergo medical examinations. The ADA contains specific provisions dealing with the ability of employers to request or obtain medical information or to require medical examinations. For example, the ADA prohibits any medical inquiries or medical examinations at the pre-offer stage of the employment application process.⁴ Genetic testing constitutes such a medical inquiry or examination; thus, under the ADA, an employer is prohibited from requiring all job applicants to undergo genetic screening.

Overview of the Genetic Information Nondiscrimination Act of 2008

The Genetic Information Nondiscrimination Act of 2008 contains three titles. Title I prohibits genetic discrimination by insurance companies and group health plans. Title II makes it unlawful for employers to discriminate based on genetic information, notwithstanding the dearth of evidence of genetic discrimination in the workplace. Title III amends the child labor damage provisions of the Fair Labor Standards Act (FLSA).

Protected Genetic Information. The law defines the term “genetic information” as information about an individual’s or a member of his or her family’s genetic tests or information about the occurrence of a disease or disorder in family members.⁵ The term does not include information about the sex or age of an individual. Nor does the term include information about physical exams or the current health status of an individual. But the proposed legislation broadly defines “family member” as all “individuals related by blood to the individual or spouse or child.”⁶ This broad definition, and others like it, could result in a proliferation of litigation under the new law.

Genetic Services. The law defines the term “genetic services” more narrowly than previous versions of the legislation. “Genetic services” means genetic testing, genetic counseling and genetic education.⁷ “Genetic testing” includes analysis of information including DNA, RNA, chromosomes, proteins, or metabolites that detects an individual’s genetic make up including mutations and chromosomal changes.⁸ Testing related to proteins or metabolites, however, that do not detect an individual’s genetic make up, mutations or chromosomal changes are excluded from the term genetic testing.⁹

Specific Prohibitions. Specifically, the Act states that it shall be an unlawful employment practice for an employer—

- to discriminate against any individual in the terms, conditions or privileges of employment because of
 - protected genetic information concerning that individual; or
 - information about genetic services for that individual or one of his or her family members;¹⁰
- to limit, segregate, or classify the employer's employees in any way that deprives any employee of employment opportunities or otherwise adversely affect his or her status as an employee, because of protected genetic information or genetic services;¹¹ or
- to request, require, collect or purchase protected genetic information with respect to an individual or a family member of the individual.¹²

Exceptions. GINA, however, sets forth several exceptions to what would otherwise constitute unlawful acquisition of genetic information. The exceptions include the following:

- where an employer inadvertently acquires the medical information of an employee's family medical history;¹³
- where an employer offers health or genetic services including as part of a wellness plan and the employee provides written authorization;¹⁴
- where an employer requests family medical history from an employee to comply with the certification requirements of the Family and Medical Leave Act (FMLA);¹⁵
- where an employer acquires documents that include family medical history, which are commercially or publicly available (excepting medical databases or court records);¹⁶
- where an employer engages in genetic monitoring of biological effects of toxic substances in the workplace, where:
 - the employer provides written notice of the genetic monitoring to the employee;
 - the employee provides written authorization or the monitoring is required by Federal or State law;
 - the employee is informed of individual monitoring results;
 - the monitoring conforms to any genetic monitoring regulations that may be promulgated by the Secretary of Labor; and
 - other than licensed health care professionals that are involved in the genetic monitoring program, the employer receives the results of the monitoring only in aggregate terms that do not disclose the identity of specific employees' DNA;¹⁷ or
- where an employer conducts analysis for law enforcement purposes.¹⁸

Confidential Recordkeeping of Genetic Information. The Act also provides that if an employer has an employee's genetic information, it must be treated as a confidential medical record and be kept in separate medical files. However, the GINA provides a safe harbor if an employer has genetic information and it "is maintained with and treated as a confidential medical record under the ADA."¹⁹

Retaliation Cause of Action. It is unlawful to discriminate against any individual because they have engaged in protected activity (*i.e.*, opposing any practice or act that is unlawful, filing a charge, or participating in an investigation or hearing).²⁰

No Disparate Impact Cause of Action. The law does not permit disparate impact claims for at least six years. Six years after the bill is enacted, an eight person commission composed of individuals selected by members of Congress will decide whether there is a need for such a cause of action under the law.²¹

Damages. An individual who prevails under Title II of the bill may receive compensatory damages (such as future pecuniary losses, emotional pain, suffering, inconvenience, mental anguish, loss of enjoyment of life, and other nonpecuniary losses) and punitive damages for violations.²² The statutory caps that apply to other nondiscrimination laws such as Title VII, which provide that the maximum amount of compensatory and punitive damages is \$300,000, also apply to damages under GINA.²³ Punitive damages are not limited to substantive discrimination, but apply to technical violations of the Act as well.

Damages under Title I, which is applicable to insurance companies and group health plans are generally limited to the remedies provisions under the Employee Retirement Income Security Act (ERISA).²⁴ For example, Title I provides that the Secretary of Labor may penalize plan sponsors of group health plans or insurers for failure to comply with the various provisions of the bill and violations of existing ERISA restrictions on genetic discrimination.²⁵ The penalty is \$100 per day during the "non-compliance period with respect to each participant or beneficiary" effected.²⁶ However, if plan sponsors or insurance companies knowingly continue to operate in violation of the bill then the penalty shall not be less than \$2,500.²⁷ Moreover, if such violations are considered "more than *de minimus*" for any year then the penalty would be \$15,000 for each participant or beneficiary effected.²⁸ Penalties that are not the result of "willful neglect", however, are capped at the lesser of 10 percent of the amount paid by the plan sponsor during the preceding year or \$500,000.²⁹ What is more, not only may violations of Title I subject companies to the penalties discussed above, but also, such companies may potentially be subject to an excise tax for the same violation under the Internal Revenue Code § 4980D.³⁰

Firewall Installed To Preclude Dual Liability for Employers. As discussed above, GINA stalled in the Senate because of concerns that employers would be subject to civil rights lawsuits—providing compensatory and punitive damages—resulting from disputes over medical coverage.³¹ In addition, there was a substantial concern that employers would be "sued twice"; not only under Title II for genetic discrimination, but also, under Title I as the employer plan sponsor of a group health plan.³² Moreover, employers could have potentially been liable for violations of the statute by third party administrators of their plans.

Responding to these concerns, a “firewall” was built between the employer and insurance provisions.³³ The purpose of the firewall is to ensure that companies are not hit with damages and penalties under both Titles I and II. Thus, Title II generally prohibits the enforcement of Title I against employers and it also excludes employers from being subject to Title I penalties.³⁴

Effective Dates. Title I becomes effective one year after the legislation is enacted.³⁵ The bill requires, under Title II, the EEOC to issue regulations within one year of enactment and Title II takes effect 18 months after GINA is enacted.³⁶ Expanding the remedies for FLSA violations of child labor laws under Title III are effective immediately upon enactment.³⁷

Concerns Regarding Implementation of the Genetic Nondiscrimination in Health Insurance and Employment Act

Because the legislation was enacted without any history of discrimination to draw from, one of the difficulties during consideration of the legislation was anticipating all of the situations to which it may apply. Thus, it is likely that, with the passage of time, new compliance issues will emerge. However, even under the legislation as finally passed, employers have a number of concerns regarding compliances issues.

Liability for Unsolicited Information. GINA defines “genetic information” so broadly that it not only includes information derived from genetic tests, but also any information about the occurrence of a disease or disorder in family members. One major concern of employers is that, while the Act provides a defense for employers who inadvertently receive genetic information (*e.g.*, routine health insurance claims, or unsolicited information concerning family histories) upon the filing of a genetic discrimination claim, the burden will still be on the employer to convince a jury that the employer’s knowledge of such information—even where obtained without solicitation— was not a factor in any adverse employment action taken after receipt of the information. This burden may be so great as to force employers to settle many of these cases rather than risk taking them to an uncertain jury.

Conflict With Other Federal Statutes. The Act allows employers to acquire possible “genetic information” for some employment-related purposes such as FMLA certifications and workers’ compensations forms. However, the bill does not specifically permit employers to discuss genetic information related to ADA accommodations, health insurance, or COBRA. An employer’s attempt to comply with those laws may result in the receipt of such information in violation of GINA.

Absence of Federal Preemption. A major omission from GINA is its failure to preempt the 35 state laws that currently exist, thus allowing a patchwork quilt of conflicting laws that could continue to proliferate. This despite that one of the legislative findings maintained that “the American public and the medical community find the existing patchwork of State and Federal laws to be confusing....”³⁸

GINA Increases Penalties for Violations of Child Labor Provisions Under the Fair Labor Standards Act

Title III of GINA amends the Fair Labor Standards Act (FLSA) to provide for increased penalties for violations of the child labor provisions. The Act increases the penalty from \$10,000 to \$11,000 for each employee subject to a violation of the child labor provisions.³⁹ In addition, the Act amends FLSA to provide for a civil penalty not to exceed \$50,000 for a violation of child labor provisions resulting in the death or serious injury of any employee under 18 years of age. This penalty may be doubled for repeated or willful violations. What is more, the FLSA was amended to provide that a civil penalty not exceed \$1,100 for each violation of the child labor damages section for repeated or willful violations of the FLSA minimum wage or overtime sections with respect to child labor.

Conclusion

While it is generally acknowledged that few, if any, employers are currently operating in a manner that would violate the legislation's basic prohibitions, GINA will require employers to closely examine their current operations to guard against inadvertent violations. Moreover, they will need to anticipate arguable violations as well in order to avoid litigation. Employers can only hope that genetic information involves such a unique situation that Congress would be unlikely to pass any other future enactments without first having a clearer picture of a need for legislation.

¹ Protecting Workers from Genetic Discrimination: Hearing on H.R. 493 Before the Subcomm. on Health, Employment, Labor and Pensions Comm. on Education and Labor, 110th Cong. (2007) (testimony of Burton J. Fishman on behalf of the Genetic Information Nondiscrimination in Employment Coalition); Andrew Pollack, Congress Near Deal on Genetic Test Bias Bill, *NEW YORK TIMES*, April 23, 2008.

² EEOC Compliance Manual (BNA), 902.8(a) (1995).

³ 42 U.S.C. § 12102(2)(C).

⁴ 42 U.S.C. § 12112(d)(2)(A).

⁵ Genetic Information Nondiscrimination Act of 2008, § 201 (4).

⁶ *Id.* at § 201 (3).

⁷ *Id.* at § 201 (6).

⁸ *Id.* at § 201 (7).

⁹ *Id.* at § 201(7)(B).

¹⁰ *Id.* at § 202 (a)(1).

¹¹ *Id.* at § 202 (a)(2).

¹² *Id.* at § 202 (b).

¹³ *Id.* at § 202 (b)(1).

¹⁴ *Id.* at § 202 (b)(2)(A-B).

¹⁵ *Id.* at § 202 (b)(3).

¹⁶ *Id.* at § 202 (b)(4).

¹⁷ *Id.* at § 202 (b)(5)(A-E).

¹⁸ *Id.* at § 202 (b)(6).

¹⁹ *Id.* at § 206 (a) (citing 42 U.S.C. 12112(d)(3)(B)).

²⁰ *Id.* at § 207 (f).

²¹ *Id.* at § 208 (a).

²² *Id.* at §207 (a)(3).

²³ 42 U.S.C. 1981a(a)(1).

²⁴ *Id.* at § 101 (e). These damage provisions are very similar to excise tax penalties under the Internal Revenue Code § 4980D.

²⁵ *Id.* at § 101 (e)(A).

²⁶ *Id.* at § 101 (e)(B).

²⁷ *Id.* at § 101 (e)(C)(i).

²⁸ *Id.* at § 101 (e)(C)(ii).

²⁹ *Id.* at § 101 (e)(D)(iii).

³⁰ *Id.* at § 103(e).

³¹ Andrew Pollack, Congress Near Deal on Genetic Test Bias Bill, *NEW YORK TIMES*, April 23, 2008 (quoting Sen. Tom Coburn (R-OK)).

³² *Id.*

³³ House Passes Landmark Ban on Genetic Discrimination, *CONGRESSIONAL QUARTERLY*, May 1, 2008.

³⁴ Genetic Information Nondiscrimination Act of 2008, § 209 (a).

³⁵ Genetic Information Nondiscrimination Act of 2008, § 105 (b)(2).

³⁶ *Id.* at §§ 212-13.

³⁷ *Id.* at § 302 (b).

³⁸ *Id.* at § 1 (5).

³⁹ 29 U.S.C. §§ 212 and 213(c)(5).