

## TOPIC:

### **GENES AT WORK - NOTHING TO BE CASUAL ABOUT: How EEOC's New Genetic Anti-Discrimination Rules Impact Colleges and Universities**

## INTRODUCTION:

Rapid advances in genetic research and testing have made it increasingly possible to detect the causes, and potential cures, for a host of diseases ranging from asthma, to diabetes, to Parkinson's disease. With these benefits, however, arise concerns that employers or health care providers could use genetic information to discriminate against individuals based on their genetic inclination toward certain diseases. To combat this discrimination, and to encourage individuals to take advantage of genetic testing without fear of jeopardizing their jobs or health insurance, Congress passed the Genetic Information Nondiscrimination Act of 2008 ("GINA" or "the Act") [\[1\]](#). The EEOC has now released its final regulations implementing GINA and providing guidance for employers [\[2\]](#).

Like all employers, colleges and universities face new compliance obligations with respect to genetic information of employees – obligations which could affect everything from office discussions about medical issues, to the breadth of information collected for college or university-sponsored employee wellness programs.

It should be noted that Title I of GINA prohibits genetic discrimination in health insurance, and Title II prohibits such discrimination in employment. This NACUANOTE focuses primarily on Title II and its effect on colleges and universities as employers. Those colleges and universities that act as insurers should also become familiar with the provisions of Title I, which include prohibitions against discrimination in group premiums by health insurers based on genetic information, the use of genetic information as a basis for determining eligibility to enroll in a health insurance plan, and the collection of genetic information in group health plan coverage [\[3\]](#).

## DISCUSSION:

### **Overview of Title II of GINA**

Title II of GINA, which prohibits genetic information discrimination in employment, has been in effect since November 2009, but the Equal Employment Opportunity Commission's ("EEOC") final regulations implementing GINA became effective on January 10, 2011. Generally, the law prohibits public and private employers from making employment decisions – including hiring, firing, promoting, or providing benefits – on the basis of genetic information [\[4\]](#). GINA further prevents employers from requesting or requiring genetic information from employees or job applicants, except in certain limited circumstances, and outlaws the disclosure or dissemination of an employee's genetic

information, with certain limited exceptions [\[5\]](#).

## “Genetic Information”

The Act broadly defines “genetic information” as information about an individual’s genetic background or the medical history or genetic background of the individual’s family members (up to and including fourth-degree relatives) [\[6\]](#). That includes information about:

- An individual’s genetic tests;
- The genetic tests of the individual’s family members; and
- The manifestation of a disease or disorder in an individual’s family members [\[7\]](#).

It is important to note that “genetic information” does not include information about any person’s age or sex, nor does it include information about an individual’s *own* manifested medical conditions. Race and ethnicity are also excluded from the definition of “genetic information” to avoid conflict with federal Equal Employment Opportunity obligations that require employers to request information on the race and ethnicity of employees [\[8\]](#).

In short, GINA is constructed to apply to any information that exposes a person’s genetic make-up and accompanying tendency to suffer from illness or disease in the future. Colleges and universities should be aware of the ways in which the requirements and prohibitions of GINA will affect their operations, particularly in regard to the acquisition of protected genetic information, which arises in a variety of contexts, including FMLA-related inquiries, office conversations about health history, and college or university-sponsored employee wellness programs.

## Acquiring or Requesting Genetic Information

GINA’s prohibition against “requesting” genetic information from employees left some employers concerned that common workplace conversation – such as inquiries about an employee’s general health, or about the condition of an employee’s sick family member – could become the basis for litigation. The EEOC regulations clarify the circumstances under which these types of discussions and related conduct can constitute the acquisition of genetic information prohibited by GINA.

### ***Water Cooler Talk and Inadvertent Acquisition***

To begin, EEOC clarified that GINA is not intended to discourage “water cooler” conversations about personal or family health issues, and inadvertent acquisition of genetic information is not prohibited. Thus, it does not violate the law when an employer “unwittingly receives otherwise prohibited genetic information” through “casual conversations with an employee or by overhearing conversations among co-workers.” [\[9\]](#)

However, if the employer, upon inadvertently acquiring protected genetic information, subsequently asks probing follow-up questions such as whether other family members also have a disclosed medical condition, or whether the individual has been tested for the condition, such questions constitute inappropriate requests for genetic information [\[10\]](#). In this way, the law draws a narrow line between permissible general inquiries, such as “How is your son?,” “How are you feeling?” and “Did they catch it early?” versus specific probing questions, which are impermissible [\[11\]](#).

### ***Acquisition of Genetic Information from Online or Public Sources***

Similar to the exception for water cooler talk, an employer does not violate GINA if a supervisor and an employee connect on a social networking site and the employee provides personal or family

medical information on her page [\[12\]](#). Likewise, GINA contains an exception for publicly available materials, so an employer would not run afoul of GINA if, for example, he learned from a newspaper article or obituary that an employee's mother died of cancer.

However, employers may not obtain protected genetic information by performing targeted internet searches designed or intended to reveal such information – even if that information is public. Thus, actively seeking out an individual's genetic information by, for instance, searching medical databases, court records, scientific research databases, or other sources would likely violate GINA.

### ***Safe Harbor Language and GINA's Interplay with the ADA and FMLA***

Another important exception under GINA provides a “safe harbor” that protects employers who may receive genetic information in response to the employer's lawful request for employee medical information following that employee's request for accommodation under the Americans with Disabilities Act (“ADA”) or a request for leave under the Family and Medical Leave Act (“FMLA”). For example, certification of an employee's request for FMLA leave to care for a family member with a serious illness will necessarily involve the disclosure of genetic information. In these and similar situations, an employer's request for information will not give rise to a GINA violation, so long as the request contains a specific affirmative warning to *not* provide genetic information, unless necessary to comply with the request [\[13\]](#).

### **GINA's Effect on College or University-Sponsored Wellness Programs**

The prohibition against acquiring genetic information also implicates employer-sponsored wellness and disease prevention programs. With the rising costs of providing health care benefits to employees, many colleges and universities have implemented targeted wellness programs as a means of encouraging employees to live healthier lifestyles and otherwise take preventive measures against the onset of illness [\[14\]](#).

Many college and university wellness programs exist as part of a group health plan under which employee participation in the program is rewarded in the form of a premium discount or cost sharing reduction. GINA adds to the legal challenges inherent in implementing these types of programs. An integral part of many wellness programs is the employee health risk assessment (“HRA”), which usually consists of a survey completed by an employee that appraises her risk for various diseases or conditions and directs her to appropriate preventive care measures or screening [\[15\]](#). Often the assessment is based on factors such as the individual's lifestyle and family medical history.

In addition, colleges and universities often use incentives to encourage their employees to complete HRAs. Offering rewards to employees who complete HRAs – such as a discount on premiums, a waiver of a deductible, or a reduction in the employee's health plan contribution – is one of the most effective ways to ensure that employees enroll in the wellness program, and 64% of employers who offer wellness programs provide these types of incentives for completing HRAs [\[16\]](#).

Given the broad definition of “genetic information” and GINA's prohibition against employers acquiring genetic information, requiring or offering incentives for employees to fill out HRAs could constitute improperly requesting genetic information and/or discriminating against employees for refusing to provide genetic information. This risk remains even if the rewards are provided to employees regardless of the content of the information provided in the HRA.

The EEOC regulations help clarify the ambiguity surrounding the propriety of employer-sponsored wellness programs and HRAs. Under these new regulations, employers may offer financial inducements to encourage participation in wellness programs, although they may not condition receipt of the reward on the provision of genetic information. Thus, if the employer offers a financial incentive for completing an HRA, the employer must specifically identify those questions regarding

family medical history or other genetic information and make clear that employees need not answer those questions to receive the inducement [\[17\]](#).

Furthermore, it does not constitute unlawful discrimination for employers to offer wellness and disease management programs (and financial incentives to participate in such programs) to individuals who, based on their voluntarily-provided genetic information, appear to be at increased risk of developing a certain health condition in the future. However, employers engaging in such targeted wellness initiatives must also offer the programs to employees with current manifested health conditions and/or those whose lifestyle choices put them at risk of acquiring a condition [\[18\]](#). For example, if an employee is offered a disease management program because her voluntarily disclosed genetic information revealed a risk of diabetes, the same program would have to be offered to other employees whose diet choices may reveal a similar risk of diabetes.

Colleges and universities should review their wellness programs in consideration of the new law and determine what changes would best effectuate their program's objectives. Most critically in terms of legal compliance, the wellness program must not require the disclosure of family medical history or other genetic information and financial incentives may not be conditioned on the disclosure of such information.

## **Confidentiality and Inadvertent Disclosure of Genetic Information**

Another important aspect of GINA pertains to confidentiality of genetic information. GINA requires that employers who possess genetic information about their employees keep such information confidential. Genetic information concerning an employee may only be disclosed 1) to the employee or her family member at the employee's written request; 2) to an occupational or other health researcher; 3) in response to a court order; 4) to a government official investigating GINA compliance if the information is relevant; 5) to comply with state or federal family and medical leave requirements; or 6) to a federal, state, or local public health agency and only with regard to information that concerns a contagious deadly disease or life-threatening illness [\[19\]](#).

In addition, GINA mandates that employers treat any genetic information they have on employees in the same special manner that employers are required to treat information concerning an employee's disability under the ADA [\[20\]](#). Employers must treat genetic information as a "confidential medical record" and must maintain it on separate forms in separate medical files, although such files need not be maintained separately from other medical records kept pursuant to the ADA [\[21\]](#).

In light of these regulations, it is all the more important for college and university administrators to educate their personnel about what qualifies as genetic information and the requirements and prohibitions of GINA. Institutions should follow specific steps to ensure that any genetic information that they do obtain from employees remains confidential and is not accidentally released to unauthorized parties. This includes keeping all employee genetic information in a separate file for the employee marked as confidential. These files must not be released, unless one of GINA's narrow exceptions applies to the disclosure.

## **CONCLUSION:**

GINA remains in its infancy, and many aspects of the law have yet to be tested in light of the EEOC implementing regulations. Still, awareness of how the new law can affect educational institutions is critical to compliance. College and university administrators must integrate the requirements of GINA into existing Equal Employment Opportunity, ADA and FMLA policies, and train supervisory and

management-level employees on the issues presented by the law. Where necessary, administrators should also adjust their employee wellness programs to comply with GINA, and otherwise carefully guard any genetic information the institution may possess.

## FOOTNOTES:

FN1. Genetic Information Nondiscrimination Act, P.L. 110-233, Title II of which is codified as 42 U.S.C. §§ 2000ff, et seq.

FN2. Regulations under Title II of the Genetic Information Nondiscrimination Act of 2008, 75 Fed. Reg. 68,912 (November 9, 2010) (codified at 29 C.F.R. Part 1635).

FN3. The Departments of Treasury, Labor, and Health and Human Services published Interim Final Rules related to Title I of GINA in October 2009. See 74 Fed. Reg. 51664 (October 7, 2009).

FN4. 42 U.S.C. § 2000ff-1. Note that GINA applies to private employers with 15 or more employees, which almost certainly places all colleges and universities within the scope of the law. GINA also covers certain public sector employers, such as public universities, employment agencies and labor organizations.

FN5. Id.

FN6. 42 U.S.C. § 2000ff(4).

FN7. “Genetic tests” are defined as any “analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.” 42 U.S.C. § 2000ff(7).

FN8. 75 Fed. Reg. 68912, 68916; 29 C.F.R. Part 1635.

FN9. 75 Fed. Reg. 68,919.

FN10. Id.

FN11. Id. at 68,920.

FN12. Id.

FN13. Id. at 68,920-21. The EEOC regulations provide the express “safe harbor” language for employers to use when warning individuals and health care providers not to respond to a request for information by revealing an individual’s protected genetic information. The regulations further provide a specific exception for the disclosure of family medical history as part of the FMLA certification process if an employee requests leave to care for an ill family member.

FN14. Wellness Programs for Colleges & Universities: What’s Working Today? Presented June 3, 2008.

FN15. Adele Nicholas, Risky Assessments: New GINA Regulations Pose Challenges to Employer Wellness Programs, INSIDE COUNSEL, January 1, 2010, Labor section, page 24.

FN16. Cari Tuna, Wellness Efforts Face Hurdle, WALL STREET JOURNAL, Feb. 1, 2010 (citing survey by PricewaterhouseCoopers LLP).

FN17. 75 Fed. Reg. at 68,923-24.

FN18. Id.

FN19. 42 U.S.C. §2000ff-5(b).

FN20. See 42 U.S.C. §2000ff-5(a) (cross-referencing the United States Code section on confidential medical records under the ADA, 42 U.S.C. §12112(d)(3)(B)).

FN21. Id.

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## RESOURCES:

### Statutes

- [The Genetic Information Nondiscrimination Act of 2008](#)

### Regulations

- [Final Rule: EEOC Regulations Under Title II of GINA](#)
- [Interim Final Rule: Departments of Treasury, Labor, and HHS Interim Final Rule regarding Title I of GINA](#)
- [Proposed Rule: HHS Proposed Rule regarding GINA and HIPAA](#)

### Guidance

- [EEOC Background Information for Final Rule on Title II of GINA](#)

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