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GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008 (GINA)

By Bonnie Jones, Human Resource Consultant

October 2012

THE UNIVERSITY of TENNESSEE 
MUNICIPAL TECHNICAL ADVISORY SERVICE

In cooperation with the Tennessee Municipal League



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GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008

On May 21, 2008, President George W. Bush signed the Genetic Information Nondiscrimination Act (GINA) into law. GINA at 42 U.S.C. 2000(ff) et seq., is an important bill because it protects employees and applicants from discrimination based on their genetic information as it pertains to health insurance coverage and employment in all 50 states. The late Senator Ted Kennedy called it “the first major new civil rights bill of the new century.”¹

GINA was enacted by Congress after the scientific community celebrated several critical successes in the field of genetics (notably, the decoding of the human genome and the creation and increased use of genomic medicine). With science advancing, so did the likelihood of a misuse of genetic information resulting in discrimination based on one’s genetic status, or the genetic health of one’s family. GINA was created to address concerns of the public about whether they may be at risk for losing employment opportunities, or being denied health insurance coverage when a genetic condition is known or determined during the course of employment or insurance coverage.

The intent of GINA was to limit the ability of employers and insurers to request, require, or purchase genetic information of individuals or their family members. GINA prohibits employers from using genetic information on applicants and employees (current and former) to make employment decisions. This includes labor union members and apprentices, and trainees.

GINA amends the Employee Retirement Income Security Act (ERISA), the Public Health Services Act (PHSA), the Health Insurance Portability and Accountability Act (HIPAA), and the Internal Revenue Code. GINA provisions were written with consideration of the named laws and final regulations are developed and enforced by Health and Human Services (HHS), the Department of Labor (DOL) and the Equal Employment Opportunity Commission (EEOC).

The ramifications for GINA violations are available under Title VII. GINA does not supersede state or local laws that may provide greater protection. Often times, GINA works concurrently with other federal laws such as HIPAA, and the Americans with Disabilities Act (ADA).

PURPOSE OF GINA: To prohibit discrimination on the basis of genetic information with respect to health insurance and employment

EMPLOYERS: Applies to employers with 15 or more employees

180 days to file a charge

FEDERAL EMPLOYEES:
45 days to contact EEOC

COVERED ENTITIES:
Employers such as employment agencies, labor organizations, and joint labor-management training and apprenticeship programs

EEOC has a new revised poster that includes GINA and other changes in federal employment discrimination.

EFFECTIVE DATES:
GINA is not retroactive.

Law passed: May 21, 2008

Effective for health insurers:
May 21, 2009

Effective for employers:
November 21, 2009

EEOC’s final regulations
effective: January 10, 2011



HIPAA

In 1996, HIPAA was passed to address concerns about discrimination based on a person's health information. According to [medscape.com](https://www.medscape.com), "HIPAA was the first step toward restricting the use of genetic information by limiting its use in setting insurance premiums and determining a person's eligibility for health insurance coverage." However, HIPAA did not prevent health insurers from charging a higher rate for a group by raising the premium when it learned that covered employees had a genetic disease or disorder. HIPAA did limit insurance companies from collecting genetic information, or requiring that a person take a genetic test before issuing health coverage.²

What is genetic discrimination?

Genetic discrimination is similar to other forms of discrimination, where people are treated unfairly because of their DNA (likelihood of getting certain diseases) or family history of a disease.

What does GINA consider family?

For purposes of GINA, consider any family members who are dependents of the primary individual (employee or applicant) as a result of marriage, birth adoption, or placement for adoption and through fourth-degree blood relatives. If the degree of blood is unknown, it is safest to assume they are protected under GINA.

EMPLOYMENT AND GINA

Title II of GINA prohibits covered entities from improper use of genetic information in employment including the application process. Employers are prohibited from using individuals' genetic information when making employment decisions such as: hiring, promotion, termination, or placement determinations. GINA sends the message that an employee or applicant's genetic information is off limits and can in no way impact an employment decision.

The law was designed to help ease concerns and encourage people to pursue genetic testing without fear of discrimination or retaliation. Prior to GINA, many Americans were simply afraid to get a genetic test for fear that their insurance would be canceled or that the results would be released to their employer, who would use it against them in the workplace.

More specifically, GINA prohibits employers and covered entities from:

- Using genetic information to make decisions regarding employment, hiring, promotion, terms or conditions of employment, privileges of employment, compensation, or termination.
- Segregating, classifying, or depriving an individual of employment opportunities on the basis of genetic information.
- Requesting requiring or purchasing genetic information on an individual or family member with rare exceptions.
- Failing or refusing to refer an individual for employment on the basis of genetic information nor can the covered entity attempt to cause an employer from discriminating against an individual on the basis of genetic information.
- Using genetic information in making decisions regarding admission to or employment in any program for apprenticeship or training and retraining, including on the job training.
- Excluding or expelling from membership, or otherwise discriminate against an individual because of genetic information.

COVERED GENETIC INFORMATION

According to EEOC, genetic information includes information about an individual's genetic tests and the genetic tests of an individual's family members, as well as family history and information about the manifestation of a disease or disorder that pertains to a person's family members such as family medical history. Family history is included in the definition of



genetic information because risk factors are often determined based on family history of diseases. Genetic information may also include a person's request for, or receipt of, genetic services, or the participation in clinical research that includes genetic services by the individual or family member of the individual, and the genetic information of a fetus carried by an individual or by a pregnant woman who is a family member of the individual and the genetic information of any embryo legally held by the individual or family member using assisted reproductive methods.³

GENETIC TESTING

Genetic tests typically look at an individual's DNA/RNA. Genetic tests look for alternations in a person's genes or changes in the level of structure of key proteins coded by specific genes. Some types of genetic testing may be: gene tests, chromosomal tests, or biochemical tests.

Genetic tests can include, but may not be limited to:

Gene tests look for signs of a disease or disorder in DNA or RNA taken from a person's bodily fluids or tissues. The tests can look for changes in gene patterns or altered chemical bases, excess copies, activity level of genes, inactive genes, or missing genes.

Chromosomal tests apply to the large DNA-containing structures in the nucleus of the cell. Humans are supposed to have 23 pairs of chromosomes; 22 pairs of autosomes, and one pair of sex cell chromosomes. Chromosomal tests look at features of an individual's chromosomes including structure, number, and arrangement. The tests may look for a chromosome missing, expanded, or being switched to a different chromosomal location. Karyotype's and fluorescent in situ hybridization (FISH) analysis may be types of tests used for chromosomal purposes.

Biochemical tests generally look at the amounts or activities of key proteins. These types of tests are commonly used in newborn screenings. The diagnosis of Phenylketonuria (PKU) is made by using a biochemical test.

EXAMPLES OF TESTS COVERED BY GINA

- BRCA1/BRCA2 or HNPCC mutations for hereditary cancers
- Carrier screening for disorders such as cystic fibrosis and fragile X syndrome
- Newborn screenings for genetic conditions
- Classifications of genetic properties of tumors to help determine therapy

Genetic testing is generally used to:

- Diagnose a person who may have symptoms of a disease or illness.
- Determine if an individual is a carrier of a genetic disease. *Some carriers will not get the disease, but may be able to pass the gene to children. Conversely, some carriers may get the disease but may not be able to pass the gene to children.*
- Diagnose unborn fetuses with genetic conditions before birth.
- Screen newborns for genetic diseases or conditions.
- Indicate if a person is pre-disposed to or inherited disposition prior to a disease starting.
- Assist health care providers with determining the best course of treatment.

While genetic testing can be a stressor, it often provides a measure of relief because individuals no longer have to live with the uncertainty that comes with not knowing if they are gene positive. Additionally, it may allow for a longer, healthier life span due to experimental medical treatments, and healthy living behaviors that may lead a person to taking steps to lower his or her chance of developing a disease.



Predictive testing can show which individuals have a higher chance of developing a disease or condition before symptoms appear. This is commonly being used for breast cancer and diabetes. Predictive testing does not conclusively provide answers, but simply looks at genetic risk factors that make one more likely to inherit a disease.

WELLNESS AND BENEFITS PROGRAMS RE-VISITED

In the last decade, there has been a significant shift on employers offering wellness incentives, and more closely managing onsite disease management programs to help reduce medical costs. GINA potentially changes the landscape of employer wellness programs, and requires employers and insurers to re-evaluate the way they administer programs, collect health information, and prevent diseases. Ultimately, GINA may challenge an employer's ability to manage diseases and chronic conditions by designating that the collection of certain health information is illegal. It is noted that the EEOC's definition of a "voluntary wellness program" for purposes of an exception to the acquisition of genetic information is inconsistent with the HIPPA requirement that permits employers access to certain information in order to administer wellness programs. The final EEOC regulations provide that a wellness program is considered voluntary if the employer "neither requires the employee to provide genetic health information nor penalizes those who do not provide the information."

NOT INCLUDED

GINA does not include protection from genetic discrimination in life insurance, disability policies, or long-term care coverage. GINA does not cover an individual's manifested disease or condition from which an individual is experiencing symptoms, has been diagnosed or for which the individual is being treated.

GINA DOES NOT APPLY

GINA does not apply to members of the United States military, veterans receiving health care through the Veteran's Administration, or to the Indian Health Service. GINA does not apply to Federal Employees Health Benefit Plans.

INTERACTION WITH STATE LAWS

The federal law sets a minimum standard of protection that must be met. Some states may have additional laws granting them protection, and this federal law does not weaken the state laws.

HARASSMENT

The law makes it clear that a covered entity may not discriminate on the basis of genetic information regarding any aspect of employment. Additionally, the law forbids harassment based on a person's genetic information or the person's family genetic information. Similar to other types of harassment, the law does not prohibit light hearted teasing or off-hand comments, or isolated incidents that are not serious in nature. Harassment is illegal when it is so severe and pervasive that it creates a hostile or offensive work environment or when the harassment results in adverse employment decisions. A harasser may be a colleague, supervisor, client, customer, or vendor.

RETALIATION

Covered entities must be careful about retaliation in the workplace. GINA makes it illegal to retaliate against any applicant or employee for filing a charge of discrimination or participating in a discrimination investigation or lawsuit.

LABOR ORGANIZATIONS

A labor organization may not exclude or expel from membership, or otherwise discriminate against a person because of genetic information.



EXCEPTIONS TO ACQUIRING GENETIC INFORMATION

It is generally unlawful for a covered entity to get genetic information.

There are six exceptions to the law:

1. Inadvertent acquisitions do not violate GINA. This includes circumstances where a manager or supervisor overhears someone talking about an individual or family member's illness.
2. Obtaining genetic information as part of health services such as wellness programs offered on a voluntary basis, if certain requirements are met.
3. Family medical history acquired in the course of Family Medical Leave Act (FMLA) administration or similar leave statutes pursuant to employer policy. However, the employer may not disclose the information.
4. Genetic information acquired through commercially and publicly available resources such as newspapers and the internet as long as the employer is not seeking the information out or pursuing sources from which they are likely to acquire genetic information.
5. Genetic information may be acquired through a genetic monitoring program that monitors the biological effects of harmful substances in the workplace where monitoring is required by law or, under carefully defined conditions where the program is voluntary.
6. Genetic information may be acquired by employers who engage in DNA testing for public safety purposes or as a forensic lab for purposes of human remains identification, but the genetic information may only be used for analysis of DNA markers for quality control to detect sample contamination (i.e., police departments, FBI etc.).

INFORMATION THAT IS NOT CONSIDERED "GENETIC"

Genetic information does not include information about gender or age. Routine tests such as cholesterol tests, liver function tests, CBC panels, and HIV tests are not covered. HIV is not itself human DNA and measuring its presence does not constitute a genetic test under the law. Additional items not protected are: DNA analysis of infectious agents such as bacteria, viruses and fungi.

Per EEOC, an employer, employment agency, labor organization, or joint labor- management committee shall not be considered to be in violation of this title based on the use, acquisition, or disclosure of medical information that is not genetic information about a manifested disease, disorder, or pathological condition of an employee or member, including a manifested disease, disorder, or pathological condition that has or may have a genetic basis.

WHAT GINA DOES NOT DO

These provisions do not:

- Prohibit medical underwriting based on current health status.
- Mandate coverage for any medical tests or treatments.
- Subject employers to remedies and procedures that are any different from those in other civil rights laws such as Title VII.
- Apply to employers with fewer than 15 employees.
- Apply to members of the military.
- Cover an individual's manifested disease or condition from which an individual is experiencing symptoms; however, it does protect information about disease in an individual's family members such as family history.
- Interfere with an employee's ability to qualify for FMLA or similar leave statues.



- Hinder an employer-sponsored wellness program or other genetic services offered by an employer.
- Interfere with an employer's ability to offer a safe and hazard free workplace.
- Preempt state law; therefore, some state's discrimination laws provide greater protection.
- Prevent a health insurer from using information about an existing condition, even if that condition has a genetic basis (i.e., breast cancer diagnosis). The insurer may need family history to approve certain procedures and testing but the information cannot be used against the individual for purposes of rate increases or cancellations/reductions in coverage.
- Restrict the practice of medicine or the authority of healthcare professionals, whether or not they are affiliated with a health plan, issuer, or employer.

For a comprehensive list of what GINA does and does not do, visit <http://www.dnapolicy.org/resources/WhatGINAdoesanddoesnotdochart.pdf>.

ADA, FMLA, AND WORKERS' COMPENSATION AS THEY INTERSECT WITH GINA

As you can imagine FMLA, ADA and Workers' Compensation commonly intersect with GINA because employers frequently handle medical information in the course of administering FMLA, ADA and Workers' Compensation.

When employers requests medical information in the course of administering ADA and FMLA, there is a potential to obtain information that could be protected by GINA, including genetic information such as: results of genetic tests for cancer genes, hereditary diseases, and other disorders. Results of genetic information on family members are also protected under GINA. GINA protections include requests for genetic information by an employer about an employee or his family member as well as genetic information regarding a fetus or embryo. It also includes the manifestation of a disease or

disorder of that may pertain to an employee or his family member. As a general rule when employers specifically ask for pertinent medical information for purposes of FMLA/ADA, the employer is acting in good faith for business and will likely fall under the GINA exception protection provision that will cover them in cases of inadvertent acquisition.

When using ADA/FMLA forms or requesting medical information, be sure to provide a disclaimer stating you are not soliciting genetic test results from employees or their family members or any information that may not be applicable to the ADA/FMLA/Workers' Compensation statutes.

Under FMLA, if an employee is seeking leave to care for a family member an employer will have access to a family member's health information that may be protected under GINA (family history of medical information specifically). This is a limited exception and only applies to an employee's family member which may include family history information. So in this case, under FMLA; an employer could legally receive information on a family member's medical history information. Note: This exception does not apply to the employee's request for their own serious health condition.

The new regulations make it clear that the employer is required to take certain steps to make sure employee medical requests do not seek genetic information.

GINA makes clear that if a covered entity acquires genetic information in response to a lawful request for medical information the acquisition of that medical information will not generally be considered a violation of GINA unless the individual directs the employer in writing or verbally not to request genetic information. In other words, the employer needs to explicitly state that genetic information on health care certification forms is not needed. Otherwise the employer may be creating a situation



where it is likely to acquire genetic information under GINA, and this information may not be protected under the inadvertent acquisition clause. Regarding Workers' Compensation, the EEOC states that "genetic information" does not include the fact that an individual has a diagnosed disease, disorder, or pathological condition therefore it is not likely that an employer dealing with workers' compensation injuries would need genetic information to assist in defense of a claim. Additionally most experts agree that workers' compensation claims are not covered by GINA.⁴

For more information on ADA please see MTAS Publication called Americans with Disabilities Act. For more information on FMLA please see the MTAS Publication called Family and Medical Leave Act.⁵

PRE-EMPLOYMENT, POST-OFFER HEALTH EXAMS/FIT FOR DUTY EXAMS

Employers have the right to ask applicants and employees to undergo physical and mental evaluations to determine fitness for duty. At a health exam a physician will often ask about family history. While this is important for the health provider in making assessments and recommendations, this information does not need to be shared with employers and is not relevant to fit for duty exams. In fact, employers should state upfront that they do not want to receive any information that may be protected under GINA, unless otherwise lawfully allowed and applicable under a federal, state, or local law or in the course of voluntary wellness programs. It is not relevant to employers that an employee has a family history of breast cancer, genetic diseases, or diabetes. What is relevant is whether the employee can perform the essential functions of the job either with or without accommodation. Employers should instruct health provider offices to not include family history or genetic information on the forms that are returned to the employer. In the event that the employer handles a large quantity of these medical forms,

the employer should consider having someone, who is well versed in GINA, screen all forms when they come in to the employer prior to distribution to the appropriate department. This may apply to ADA, FMLA and other health forms as well.

HEALTH INSURERS

Health insurers may not require individuals to provide their genetic information or the genetic information of a family member to the insurer for eligibility, coverage, underwriting, or premium setting standards. Health insurers may not request or require that an individual or an individual's family member undergo a genetic test.

RESEARCH EXCEPTION

There is a research exception. For joint research activities covered by health insurers and other external research entities, a health insurer in either the group or individual market may request, but not require, in writing that an individual undergo a genetic test. The individual may voluntarily elect to participate in such a genetic test, but noncompliance must have no negative affect on the premium or enrollment status of the individual. Genetic information may only be used for research. Genetic information may not be used for underwriting purposes.

CONFIDENTIALITY

An individual's medical information must be maintained in separate files and be kept confidential. Genetic information may not be disclosed except at the individual's written request or in response to a court order. In addition an employer may be required to provide information to federal, state or local authorities.

EXAMPLES OF GENETIC DISCRIMINATION PROHIBITED BY GINA

Jane Smith, a senior accountant with Company X was fired after her employer learned she was the primary caregiver of a mother with Huntington's



disease. Huntington's disease carries a 50 percent chance of developing the disease when one parent is gene positive. Because of her family history, Jane has a 50 percent chance of developing the disease. Shortly after she filed FMLA papers to care for her ill mother, Jane was terminated.

John Brown, a radiologist tech at Community Hospital was diagnosed with colon cancer and took leave from work to receive treatment and recover. When John returned to work, he was told he would have to undergo a medical examination. John was told that if he refused to submit to the examination he would be terminated. John later learned that his employer was administering genetic tests to employees without their consent to identify a possible genetic predisposition to cancers as a defense to workers' compensation claims.

Sara Jones, a receptionist at a corporate headquarters for a sports company was undergoing genetic testing to see if she had a high risk of inheriting breast cancer, a disease which took her mother and aunt last year. Sara tested positive for a mutation in her genes showing she would likely inherit this form of cancer. Her employer then drastically increased her health insurance premiums in response to the genetic tests results.

Mitch Evans, a firefighter with the local fire department carries a gene for a rare syndrome that can cause sudden cardiac death. At open enrollment the following year Mitch switched group insurance companies. His new plan found out about the genetic syndrome and refused to cover him.

These are all examples of a covered entity violating GINA.

ENFORCEMENT

GINA will be enforced by several federal agencies. These agencies include: HHS, DOL, the Department

of the Treasury (DOT), and EEOC. Corrective actions will be taken and financial penalties will apply for those who violate GINA.

FREQUENTLY ASKED QUESTIONS

Primary source: <http://www.dol.gov>

Q: Genetic information includes information about an individual's genetic services and tests. What do these include?

Genetic services mean genetic tests, genetic counseling, or genetic education. Genetic test means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, if the analysis detects genotypes, mutations, or chromosomal changes. A genetic test does not include an analysis of proteins or metabolites directly related to a manifested disease, disorder, or pathological condition.

Therefore, some examples of genetic tests are tests to determine whether an individual has a BRCA1, BRCA2, or colorectal cancer genetic variant. In contrast, an HIV test, complete blood count, cholesterol test, liver function test, or test for the presence of alcohol or drugs is not a genetic test.

Q: Genetic information includes an individual's genetic tests and information about the manifestation of a disease or disorder in an individual's family member. A genetic test does not include an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition. What is a manifested disease?

A manifested disease is a disease, disorder, or pathological condition for which an individual has been or could reasonably be diagnosed by a health care professional (with appropriate training and expertise in the field of medicine involved).



A disease is not manifested if a diagnosis is based principally on genetic information. For example, an individual whose genetic tests indicate a genetic variant associated with colorectal cancer and another that indicates an increased risk of developing cancer, but who has no signs or symptoms of disease and has not and could not reasonably be diagnosed with a disease does not have a manifested disease.

While plans and issuers are prohibited from adjusting group premiums or contributions based on genetic information, plans and issuers can increase the premium or contribution based on the manifested disease or disorder of an individual enrolled in the plan. This is because information about an individual's manifested disease or disorder is not genetic information with respect to that individual.

Q: Can an individual's doctor or other health care provider request that the individual undergo a genetic test?

Generally, yes. GINA prohibits a group health plan from requesting or requiring an individual or a family member of an individual undergo genetic tests. Nonetheless, under GINA, a health care professional who is providing health care services to an individual can request that an individual undergo a genetic test. A health care professional includes but is not limited to a physician, nurse, physician's assistant, or technicians that provide health care services to patients.

For example, if during the course of a routine physical exam, a physician learns that an individual has family medical history indicating a potential risk for Huntington's disease, the physician can recommend that the individual undergo a related genetic test. This would not violate GINA. This would be true even if the doctor were employed

by an HMO, so long as the physician was providing health care services to the individual for whom the genetic test was recommended.

Q: Can a health plan obtain the results of a genetic test to make a determination regarding payment of a claim for benefits under the plan?

Generally, yes. If a plan conditions payment for an item or service based on medical appropriateness and the medical appropriateness depends on the genetic makeup of the patient, then the plan is permitted to condition payment for the item or service on the outcome of a genetic test. The plan may also refuse payment in that situation if the patient does not undergo the genetic test. The plan may request only the minimum amount of information necessary to make a determination regarding payment.

Q: If a plan normally covers mammograms for participants and beneficiaries starting at age 40, but covers them at age 30 for individuals with a high risk of breast cancer, may the plan require that an individual under 40 submit genetic test results or family medical history as evidence of high risk of breast cancer, in order to have a claim for a mammogram paid?

Generally, yes. Under GINA, a plan may request and use the results of a genetic test to make a determination regarding payment, as long as the plan requests only the minimum amount of information necessary. Plans may also request genetic information for the purpose of determining the medical appropriateness of a treatment or service. Because the medical appropriateness of the mammogram depends on the patient's genetic makeup, the minimum amount of information necessary for determining payment of the claim may include the results of a genetic test or the individual's family medical history.



Q: Can a plan request that a participant or beneficiary undergo a genetic test for research purposes?

Under GINA, a plan is permitted to request, but not to require, that a participant or beneficiary undergo a genetic test for research purposes if the following four requirements are met:

- The plan makes the request pursuant to research. (Research is defined in 45 CFR 46.102(d)). The research must comply with 45 CFR Part 46 or equivalent Federal regulations and any applicable State or local law or regulation for the protection of human subjects in research.
- The plan must make the request for the genetic test in writing and clearly indicate to each participant and beneficiary that the request is voluntary and will have no effect on eligibility.
- No genetic information collected pursuant to this research exception can be used for underwriting purposes.
- The plan must complete a copy of the Notice of Research Exception under GINA and provide the notice to the address specified in the instructions.

Q: Can a plan require an individual to complete a health risk assessment (HRA) prior to or as part of the enrollment process for the plan?

GINA prohibits a plan from collecting genetic information (including family medical history) prior to or in connection with enrollment. Thus, under GINA, plans and issuers must ensure that any HRA conducted prior to or in connection with enrollment does not collect genetic information, including family medical history.

Under GINA, there is an exception for genetic information that is obtained incidental to the collection of other information, if 1) the genetic

information that is obtained is not used for underwriting purposes and 2) if it is reasonable to anticipate that the collection will result in the plan receiving health information, the plan explicitly notifies the person providing the information that genetic information should not be provided. Therefore, a plan conducting an HRA prior to or in connection with enrollment, should ensure that the HRA explicitly states that genetic information should not be provided.

Q: Can a plan require that an individual complete a health risk assessment (HRA) that requests family medical history in order to receive a wellness program reward, such as a financial incentive, in return for the completion of the HRA?

GINA prohibits a plan from collecting genetic information (including family medical history) prior to or in connection with enrollment; or at any time for underwriting purposes.

Because completing the HRA results in a reward, the request is for underwriting purposes and is prohibited.

A plan may use an HRA that requests family medical history, if it is requested to be completed after and unrelated to enrollment and if there is no premium reduction or any other reward for completing the HRA.

A plan may offer a premium discount or other reward for completion of an HRA that does not request family medical history or other genetic information, such as information about any genetic tests the individual has undergone. The plan should ensure that the HRA explicitly states that genetic information should not be provided. This is because GINA provides an exception for genetic information that is obtained incidental to the collection of



other information, if 1) the genetic information that is obtained is not used for underwriting purposes and 2) if in connection with any collection it is reasonable to anticipate that health information will be received, the collection explicitly states that genetic information should not be provided.

Plans may use two separate HRAs; one that collects genetic information, such as family medical history, which is conducted after and unrelated to enrollment and is not tied to a reward, and another HRA that does not request genetic information, which can be tied to a reward. In addition, under GINA group health plans may also reward:

1. Participation in an annual physical examination with a physician (or other health care professional) who is providing health care services to the individual, even if the physician may ask for family medical history as part of the examination;
2. More favorable cost-sharing for preventive services, including genetic screening; and
3. Participation in certain disease management or prevention programs. The incentives to participate in such programs must also be available to individuals who qualify for the program but have not volunteered family medical history information through an HRA.

Q: Is there an exception to GINA for small plans?

No. There is no exception for very small health plans or those less than two participants.

Q: How many employees does an employer have to employ to be covered under GINA?

Employers who have 15 or more employees working for at least 20 or more calendar weeks in the current or preceding calendar year.

Q: Who is considered a covered family member under GINA?

Any person who is within a fourth-degree relation of the individual. The EEOC's proposed regulations further define "family member" as a person who is or becomes related through marriage, birth, adoption, or placement for adoption.

Q: When can an employer, employment agency, labor organization or training program have access to genetic information?

When the information is publicly available or when the information is provided inadvertently as part of the person's medical history or the medical history of a family member. Another possibility is when the person's written authorization is obtained as part of an employer-sponsored genetic monitoring program concerning toxic substances in the workplace.

In addition, when the employer offers health or genetic services, including services offered as part of a wellness program which includes the person's written authorization. Lastly, where the employer operates as law enforcement and requires the person's DNA for quality control purposes in the forensic lab or human remains identification settings.

For more information on GINA, visit <http://www.eeoc.gov/laws/types/genetic.cfm>.



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END NOTES

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