

**SEIZING THE MOMENT: Building a Broader Labor Movement**

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What Union Lawyers Need to Know about  
the Americans with Disabilities Act Amendments Act (ADAAA)

and

the Genetic Information Nondiscrimination Act (GINA)  
(Regulations and Litigation)

**GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008 (GINA)**

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## **GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008 (GINA)<sup>1</sup>**

### **I. Introduction**

- A. The Genetic Information Nondiscrimination Act (“GINA”) and accompanying regulations are intended to provide individuals with legal protection against discrimination based on genetic information in health insurance and employment.
  
- B. While some non-discrimination language for genetic information did exist prior to GINA, the previous State and Federal laws were thought to be confusing and inadequate. GINA establishes a national and uniform standard to fully protect the public from discrimination and allay concerns of potential discrimination. With this legal protection, individuals can take advantage of genetic testing, technologies, research and new therapies without fear of accompanying discrimination.

### **II. Title I – Genetic Discrimination in Health Insurance**

- A. Statutory Amendments
  - i. 26 U.S.C. § 9802
    - 1. Amended Internal Revenue Code
  
  - ii. 29 U.S.C. § 1182
    - 1. Amended ERISA
  
  - iii. 42 U.S.C. § 300
    - 1. Amended Public Health Service Act
  
  - iv. 42 U.S.C. § 1395
    - 1. Amended Social Security Act
  
  - v. 42 U.S.C. § 1320

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<sup>1</sup> Jules L. Smith, Partner, Blitman & King LLP and Bryan T. Arnault, Blitman & King LLP.

1. Amended Health Insurance Portability and Accountability Act (“HIPAA”)
- B. Generally, Title I prohibits health insurers from requiring individuals to provide their genetic information or the genetic information of a family member to the insurer for eligibility, coverage, underwriting, or premium-calculation determinations.
- i. GINA does not cover 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.
  - ii. GINA does not include protections from genetic discrimination in life, disability or long-term care insurance.
- C. Relevant Definitions
- i. Family Member – broadly defined as a dependent, including those adopted, or any individual up to a fourth-degree relative
    1. Includes genetic information of any fetus carried by a pregnant woman and any embryo legally held by an individual or family member when utilizing assisted reproductive technology
  - ii. Genetic Test – an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes

1. Excludes protein or metabolite analysis that does not detect genotypes, mutations or chromosomal changes; or analysis of proteins directly to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved

- iii. Genetic Information – with respect to any individual, information about their genetic tests, the genetic tests of family members, and the manifestation of a disease or disorder in family members

1. Excludes information about the sex or age of any individual

2. Exception exists for incidental collection of information

D. Prohibitions

- i. A group health plan may not adjust premium or contribution amounts for the group covered under such plan on the basis of genetic information.

1. However, does not limit health insurer offering a group health plan to increase the premium based on the manifestation of a disease or disorder.

- ii. A group health plan shall not request or require an individual or a family member of such individual to undergo a genetic test, or request, require or purchase genetic information with respect to any individual prior to their enrollment under the plan or coverage in connection with such enrollment.

1. Research exception exists where disclosure is voluntary and the information is not used for underwriting or will not have an effect on enrollment status or premium or contribution amounts.
  2. Again, if collection is incidental, not a violation.
- iii. A health insurance issuer offering health insurance coverage in the individual market may not establish rules for eligibility (including continued eligibility) of any individual to enroll in individual health insurance coverage based on genetic information.
1. However, this does not preclude a health insurance issuer from establishing rules for eligibility for an individual to enroll in individual health insurance coverage based on the manifestation of a disease or disorder in that individual, or in a family member of that individual where such family member is covered under the policy that covers such individual.
- iv. A health insurance issuer offering health insurance coverage in the individual market shall not adjust premium or contribution amounts for an individual on the basis of genetic information concerning the individual or a family member of the individual.
1. However, this does not preclude a health insurance issuer from adjusting premium or contribution amounts for an individual on the basis of a manifestation of a disease or disorder in that individual or family member covered under the individual's policy.

2. In such a case, the manifestation of a disease or disorder in one individual cannot also be used as genetic information about other individuals covered under the policy issued to such individual and to further increase premiums or contribution amounts.
- v. A health insurance issuer offering health insurance coverage in the individual market may not, on the basis of genetic information, impose any preexisting condition exclusion.
  1. However, does not preclude health insurer from imposing preexisting condition exclusion for an individual with respect to health insurance coverage on the basis of a manifestation of a disease or disorder in that individual.
- vi. A health insurance issuer offering health insurance coverage in the individual market shall not request or require an individual or a family member of such individual to undergo a genetic test; or request, require or purchase genetic information with respect to any individual for underwriting purposes.
  1. Exception for research where voluntary, and is not used for underwriting purposes.
- vii. An issuer of a Medicare supplemental policy shall not deny or condition the issuance or effectiveness of the policy (including exclusion of benefits based on pre-existing condition) and shall not discriminate in the pricing

of the policy (including the adjustment of premium rates) of an individual on the basis of genetic information.

1. However, issuer of a Medicare supplemental policy may, to the extent permitted otherwise, deny or condition issuance based on the manifestation of a disease or disorder or increase the premium based on the manifestation of a disease or disorder.

viii. Issuer of Medicare supplemental policy may not request or require individual or family member to undergo a genetic test, or shall not request, require or purchase genetic information for underwriting purposes.

1. However, research exception where voluntary and informed, and does not affect enrollment status or premium or contribution amounts.

2. Exception for incidental collection also exists.

### **III. Title II – Genetic Discrimination in Employment**

A. Statutory Codification

i. 42 U.S.C. § 2000ff

1. Amended Civil Rights Act of 1964

B. Accompanying Regulations

i. 29 C.F.R. § 1635

- C. Generally, Title II prohibits the use of genetic information to make an employment decision because genetic information does not provide any information about an individual's current ability to work.
- D. Definitions
  - i. Employee. Broadly defined and incorporates by reference previous statutory definitions, including:
    - 1. Employee – defined by § 701(f) or 717(a) of the Civil Rights Act of 1964
    - 2. State Employee – Government Employee Rights Act of 1991
    - 3. Covered Employee – Congressional Accountability Act of 1995
    - 4. Covered Employee – 3 U.S.C. § 411(c)
  - ii. Employer. Broadly defined to incorporate previous statutory definitions, including:
    - 1. Employer – defined by § 701(b) and § 717(a) Civil Rights Act of 1964 (42 U.S.C. §§ 200e, 200e-16(a))
      - a. Employer must have 15 or more employees under this definition
    - 2. Entity employing a State employee – Government Employee Rights Act of 1991
    - 3. Employing office – Congressional Accountability Act of 1995
    - 4. Employing Office – 3 U.S.C. § 411(c)
  - iii. Employment Agency

1. Defined by § 701 of the Civil Rights Act of 1964
  - iv. Labor Organization
    1. Defined by § 701 of the Civil Rights Act of 1964
  - v. Family Member – dependent of an individual or any other individual up to a fourth-degree relative
    1. Includes the genetic information of a fetus or embryo of a pregnant individual or family member or that which is lawfully held by an individual or family member using assisted reproductive technology
  - vi. Genetic Test – analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes
    1. Does not mean an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes
  - vii. Genetic Information – information about an individual’s genetic tests, genetic tests of family members of such individual, and the manifestation of a disease or disorder in family members of such individual
    1. Excludes sex and age of any individual
- E. Prohibited Practices
- i. Unlawful for an employer, employment agency, or labor organization to fail or refuse to hire, or to discharge, any employee, or otherwise to discriminate against any employee with respect to the compensation,

terms and conditions, or privileges of employment of the employee, because of genetic information with respect to the employee.

1. Includes harassment
- ii. Unlawful for an employer, employment agency, or labor organization to limit, segregate, or classify the employees of the employer in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the status of the employee as an employee, because of genetic information with respect to the employee.
- iii. Unlawful for an employer, employment agency, labor organization, or joint labor-management committee to request, require or purchase genetic information with respect to an employee or family member.

1. Exceptions

- a. Inadvertently requesting or requiring family medical history of the employee or family member of the employee
- b. A health or genetic services offered by employer, employment agency, labor organization, or joint labor-management committee as part of a wellness program, where employee provides prior, knowing, voluntary, and written authorization, only the employee and the licensed health care professional receive individually identifiable

information concerning the results of such services and any individually identifiable genetic information is only available for the purposes of the wellness program

- c. A Family and Medical Leave Act certification request by employer, employment agency, labor organization, or joint labor-management committee that requires family medical history be shared
- d. Commercially and publicly available information purchased by employer, employment agency, labor organization, or joint labor-management committee that include family medical history
- e. Where a genetic monitoring of workplace is necessary for biological effects of toxic substances in the workplace, if:
  - i. Employer, employment agency, labor organization, or joint labor-management committee provides written notice of the genetic monitoring;
  - ii. Employee provides prior, knowing, voluntary and written authorization or genetic monitoring required by State or Federal law;
  - iii. Employee informed of individual monitoring results;

- iv. Monitoring in compliance with state or federal regulations; and
    - v. Results received by employer, employment agency, labor organization, or joint labor-management committee are in the aggregate and do not disclose the identity of specific employees
  - f. The employer, employment agency, labor organization, or joint labor-management committee conducts DNA testing for law enforcement or human remains identification purposes, and request or requires employee genetic information only to the extent that the genetic information is used for analysis of DNA identification markers for quality control to detect sample contaminants.
- iv. Unlawful employment practice for any employer, labor organization, or joint labor-management committee controlling apprenticeship or other training or retraining, including on-the-job training programs, to discriminate against any individuals with respect to the individual in admission to, or employment in, any program established to provide apprenticeship or other training and retraining.
- v. Unlawful employment practice for any employer, labor organization, or joint labor-management committee controlling apprenticeship or other training or retraining, including on-the-job training programs, to limit,

segregate, or classify the applicants for or participants in such apprenticeship or other training or retraining, or fail or refuse to refer for employment any individual, in any way that would deprive or tend to deprive any individual of employment opportunities, or adversely affect the status of the individual as an employee, because of genetic information.

- vi. Unlawful employment practice for any employer, labor organization, or joint labor-management committee controlling apprenticeship or other training or retraining, including on-the-job training programs, to cause or attempt to cause an employer to discriminate against an applicant for or a participant in such apprenticeship or other training or retraining in violation of the title.
- vii. An employer, employment agency, labor organization, or joint labor-management committee in possession of genetic information about an employee or member shall maintain the information on separate forms and in separate medical files and be treated as a confidential medical record of the employee or member.
  - 1. Compliance will be found where genetic information is maintained with and treated as a confidential medical record under section 102(d)(3)(B) of the Americans with Disabilities Act.
    - a. Can be kept in the same file as other medical information in compliance with the ADA.

2. Genetic information shall not be disclosed except:
  - a. To the employee or member of a labor organization (or family member if the family member is receiving genetic services) at the written request of the employee or member of such organization;
  - b. To an occupational or other health researcher if in compliance with 45 C.F.R. Pt. 46;
  - c. In response to a court order, and then releasing only that information expressly authorized by the order and must provide notice to employee or member if without knowledge of order;
  - d. To government officials investigating compliance with this Title II;
  - e. To extent disclosure is made in connection with the employee's compliance with the certification provisions of the FMLA or other State family and medical leave laws; or
  - f. To a Federal, State, or local public health agency only with regard to genetic information that concerns a contagious disease presenting an imminent hazard of death or life-threatening illness, and that the employee whose family member(s) is the subject of a disclosure under this paragraph is notified of such disclosure

3. HIPAA Interplay

- a. Does not prohibit a covered entity under the statute from any use or disclosure of health information that is authorized for the covered entity under HIPAA

F. Remedies and Enforcement

- i. EEOC has jurisdiction to investigate and enforce the Act
- ii. Employees are entitled to the same statutory protection afforded under the various statutes protecting employees; no new enforcement mechanism created, just expanding those already in existence
1. Employees are covered by the same remedial procedures as for violations of Civil Rights Act of 1964.
  2. Employees are covered by the same remedial procedures as outlined in the Government Employee Rights Act of 1991.
  3. Employees are covered by the same remedial procedures as outlined in the Congressional Accountability Act of 1995.
  4. Employees are covered by the same remedial procedures as outlined in chapter 5 of Title 3.
  5. Employees are covered by the same remedial procedures as outlined in section 717 of the Civil Rights Act of 1964.
- iii. GINA also includes a prohibition against retaliation towards any individual because such individual opposed any act or practice made unlawful under GINA, or because an individual made a charge, testified, assisted,

or participated in any manner in an investigation, proceeding, or hearing  
under GINA

- iv. No valid cause of action exists under the Act for disparate impact on the  
basis of genetic information

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