Legislation & Regulations

Federal Actions

Genetic Information; Employment

The Equal Employment Opportunity Commission’s final rule implementing Title II of the Genetic Information Nondiscrimination Act (GINA) of 2008, 42 U.S.C. §2000ff et seq., protects job applicants, current and former employees, labor union members, and apprentices and trainees from discrimination based on genetic information in hiring, discharge, compensation, and employment terms, conditions, or privileges. 75 Fed. Reg. 68912 (Nov. 9, 2010).

Genetic information includes information (1) from the genetic tests of the applicant/employee or his or her family member and family medical history; (2) about the applicant/employee’s or family member’s request for, or receipt of, genetic services; and (3) of a fetus carried by, or an embryo held by, the applicant/employee or family member. Family members are dependents, i.e., individuals who are or will become related to the applicant or employee through marriage, birth, adoption, or placement for adoption, as well as persons related from the first- to the fourth-degree of an individual. Entities subject to Title II include employers (private sector, state and local government, Congressional employers, executive branch, federal/civil service), as well as employment agencies, labor organizations, and joint labor-management training and apprenticeship programs. There is no individual liability under GINA.

Title II does not apply to uses and disclosures of health information that are governed by the Privacy Rule of the Health Insurance Portability and Accountability Act of 1996. Moreover,
GINA does not limit the rights or protections of a person under any other federal, state, or local law that provides equal or greater protection, including the Americans with Disabilities Act, 42 U.S.C. §12101 et seq.; the Rehabilitation Act, 29 U.S.C. §701 et seq.; and state and local laws prohibiting either genetic or disability discrimination. Remedies for GINA violations include compensatory and punitive damages; reasonable attorneys’ and expert fees; and injunctive relief, including reinstatement and hiring, back pay, and other equitable remedies.

A covered entity is prohibited from limiting, segregating, or classifying individuals because of genetic information, unless the entity limits an individual’s job duties based on genetic information because it was required to do so by a law or a regulation mandating genetic monitoring, such as Occupational and Safety Health Administration regulations. However, neither the statute nor the final regulation creates a cause of action for disparate treatment.

A covered entity is also prohibited from requesting, requiring, or purchasing genetic information, unless the entity inadvertently requests or requires genetic information from the individual or family member. This prohibition controls during the interactive process used to determine an appropriate reasonable accommodation. “Request” includes conducting an Internet search on an individual in a way that is likely to result in a covered entity obtaining genetic information; actively listening to third-party conversations or searching an individual’s personal effects in order to obtain genetic information; and making requests for information about an individual’s current health status in a way that is likely to result in a covered entity obtaining genetic information. The inadvertent acquisition exception also applies where, for example, an entity learns about genetic information by overhearing a conversation between coworkers or from a social media platform that the entity was granted permission to access by the creator of the profile at issue. In general, if the entity acquires genetic information in response to a lawful request for medical information—for example, in connection with a request for Family and Medical Leave Act (FMLA) leave—that acquisition is not considered inadvertent, unless the entity directs the individual and/or health care provider from whom it requested medical information not to provide genetic information. However, failure to give such notice does not prevent the entity from establishing that receipt of genetic information was inadvertent, if its medical information request was not “likely to result in a covered entity obtaining genetic information.”
Another exception exists for genetic information that an entity acquires through commercially and publicly available sources, as long as the entity does not research the sources with the intent of acquiring genetic information, or access sources that are likely to include such information. Potential sources include newspapers, magazines, periodicals, and books, as well as websites or social networking sites that simply require users to obtain a username and/or password— rather than require permission from the creator of the profile— to gain access. Nonetheless, an entity is prohibited from discriminating against an individual based on information from such sources.

Furthermore, a covered entity is barred from discriminating against persons who oppose unlawful acts under GINA or file a charge, testify, assist, or participate in an investigation or proceeding under GINA. “Because Congress adopted in GINA the language of the anti-retaliation provision in Title VII of the Civil Rights Act of 1964, the Commission believes that Congress intended the standard for determining what constitutes retaliatory conduct under GINA to be the same as the standard under Title VII, as announced by the Supreme Court in Burlington Northern & Santa Fe Ry. v. White, 548 U.S. 53 (2006)” : Whether the action “well might have ‘dissuaded a reasonable worker from making or supporting a charge of discrimination.’”

Furthermore, a covered entity that possesses genetic information about an employee must keep it confidential and, if the information is written, must keep it apart from other personnel files in separate medical files. Entities may disclose genetic information to: the individual to whom it relates, if he or she requests disclosure in writing; an occupational or other health researcher if the research complies with 45 C.F.R. pt. 46, which regulates research involving humans; and government officials investigating GINA. Disclosure is also allowed to comply with a court order, provided that the subject of the disclosure is notified, as well as to support an employee’s compliance with the certification provisions of the FMLA. Finally, disclosure of family medical history to federal, state, or local public health officials in connection with a contagious disease that presents an imminent hazard of death or life-threatening illness is permitted, provided that the entity notifies the individual whose family member is the subject of the disclosure.