

Definitions

For the purpose of the Genetic Information Nondiscrimination Act (GINA), “genetic information” means information about:

1. An individual’s genetic tests;
2. The genetic tests of that individual’s family members;
3. The manifestation of disease or disorder in family members of the individual (family medical history);
4. An individual’s request for or receipt of genetic services, or the participation in clinical research that includes genetic services by the individual or a family member of the individual; or
5. 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 an assisted reproductive technology.

“Genetic information” **does not include** information about the sex or age of the individual, the sex or age of family members, or information about the race or ethnicity of the individual or family members that is not derived from a genetic test.

“Genetic test” means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes. Genetic tests include, for example:

1. A test to determine whether someone has the BRCA1 or BRCA2 variant evidencing a predisposition to breast cancer, a test to determine whether someone has a genetic variant associated with hereditary nonpolyposis colon cancer, and a test for a genetic variant for Huntington’s Disease;
2. Carrier screening for adults using genetic analysis to determine the risk of conditions such as cystic fibrosis, sickle cell anemia, spinal muscular atrophy, or fragile X syndrome in future offspring;
3. Amniocentesis and other evaluations used to determine the presence of genetic abnormalities in a fetus during pregnancy;
4. Newborn screening analysis that uses DNA, RNA, protein, or metabolite analysis to detect or indicate genotypes, mutations, or chromosomal changes, such as a test for PKU performed so that treatment can begin before a disease manifests;
5. Pre-implantation genetic diagnosis performed on embryos created using in vitro fertilization;

6. Pharmacogenetic tests that detect genotypes, mutations, or chromosomal changes that indicate how an individual will react to a drug or a particular dosage of a drug;
7. DNA testing to detect genetic markers that are associated with information about ancestry; and
8. DNA testing that reveals family relationships, such as paternity.

Examples of tests or procedures that are not genetic tests are:

1. An analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes;
2. A medical examination that tests for the presence of a virus that is not composed of human DNA, RNA, chromosomes, proteins, or metabolites;
3. A test for infectious and communicable diseases that may be transmitted through food handling;
4. Complete blood counts, cholesterol tests, and liver-function tests.

A test for the presence of alcohol or illegal drugs is not a genetic test. However, a test to determine whether an individual has a genetic predisposition for alcoholism or drug use is a genetic test.

Notices

The Superintendent or designee shall post in conspicuous places on school premises, where notices to employees and applicants for employment are customarily posted, a notice setting forth excerpts from or summaries of the pertinent provisions of the GINA regulation and information pertinent to the filing of a complaint.

Prohibited Practices

Discrimination

[SCHOOL] (the “School”) shall not discriminate against an individual on the basis of genetic information in regard to hiring, discharge, compensation, or terms, conditions, or privileges of employment.

Retaliation

The School shall not discriminate against an individual because the individual has opposed any act or practice made unlawful by GINA or because the individual made a charge, testified, assisted, or participated in any manner in an investigation, proceeding, or hearing under GINA.

Acquisition

Except as set forth below or otherwise provided in the GINA regulations, the School shall not request, require, or purchase genetic information of an individual or family member of the individual.

“Request” includes:

1. Conducting an Internet search on an individual in a way that is likely to result in the School’s obtaining genetic information;
2. Actively listening to third-party conversations or searching an individual’s personal effects for the purpose of obtaining genetic information; and
3. Making requests for information about an individual’s current health status in a way that is likely to result in the School’s obtaining genetic information.

Disclosure

Except as set forth in the GINA regulations, the School shall not disclose the genetic information of an employee, regardless of how the School obtained the information.

Manifested Condition

The School shall not be considered to be in violation of the GINA regulations based on the use, acquisition, or disclosure of medical information about a manifested disease, disorder, or pathological condition of an employee, even if the disease, disorder, or pathological condition has or may have a genetic basis or component. However, genetic information about a manifested disease, disorder, or pathological condition is subject to the requirements and prohibitions of GINA.

“Manifestation” or “manifested” means, with respect to a disease, disorder, or pathological condition, that an individual has been or could reasonably be diagnosed with the disease, disorder, or pathological condition by a health-care professional with appropriate training and expertise in the field of medicine involved. A disease, disorder, or pathological condition is not manifested if the diagnosis is based principally on genetic information.

Inadvertent Acquisition

The general prohibition against requesting, requiring, or purchasing genetic information does not apply where the School inadvertently requests or requires genetic information of the individual or family member of the individual. This exception applies in situations where a manager or supervisor learns genetic information about an individual by:

1. Overhearing a conversation between the individual and others;
2. Receiving the information during a casual conversation, including in response to an ordinary expression of concern that is the subject of the conversation. This exception does not apply where a supervisor follows up with questions that are probing in nature, such as whether other family members have the condition or whether the individual has been tested for the condition, because the supervisor or official should know that these questions are likely to result in the acquisition of genetic information;
3. Receiving unsolicited information (e.g., where a supervisor receives an unsolicited e-mail about the health of an employee's family member from a co-worker); or
4. Accessing a social media platform that the supervisor was given permission to access by the creator of the profile at issue (e.g., a supervisor and employee are connected on a social networking site and the employee provides family medical history on his page).

Requests for Medical Information

If the School acquires genetic information in response to a lawful request for medical information, the acquisition of genetic information will not generally be considered inadvertent unless the School directs the individual and/or health-care provider from whom it requested medical information not to provide genetic information.

Situations involving lawful requests for medical information include, for example:

1. Requests for documentation to support a request for reasonable accommodation under federal, state, or local law;
2. Requests for medical information as required, authorized, or permitted by federal, state, or local law, such as where an employee requests leave under the Family and Medical Leave Act (FMLA) to attend to the employee's own serious health condition or where an employee complies with the FMLA's employee return to work certification requirements; or
3. Requests for documentation to support leave that is not governed by federal, state, or local laws requiring leave, as long as the documentation required to support the request otherwise complies with the requirements of the Americans with Disabilities Act (ADA) and other laws limiting the School's access to medical information.

SAFE HARBOR

Any receipt of genetic information in response to a request for medical information shall be deemed inadvertent if the School uses language such as the following:

“The Genetic Information Nondiscrimination Act of 2008 (GINA) prohibits employers and other entities covered by GINA Title II from requesting or requiring genetic information of an individual or family member of the individual, except as specifically allowed by this law. To comply with this law, we are asking that you not provide any genetic information when responding to this request for medical information. ‘Genetic information,’ as defined by GINA, includes an individual’s family medical history, the results of an individual’s or family member’s genetic tests, the fact that an individual or an individual’s family member sought or received genetic services, and genetic information of a fetus carried by an individual or an individual’s family member or an embryo lawfully held by an individual or family member receiving assistive reproductive services.”

The School’s failure to give such a notice or to use this or similar language will not prevent the School from establishing that a particular receipt of genetic information was inadvertent if the request for medical information was not likely to result in the School’s obtaining genetic information (for example, where an overly broad response is received in response to a tailored request for medical information).

Employment Examinations

The prohibition on acquisition of genetic information applies to medical examinations related to employment. The School shall tell health-care providers not to collect genetic information, including family medical history, as part of a medical examination intended to determine the ability to perform a job.

Remedial Measures

The School shall take additional reasonable measures within its control if it learns that genetic information is being requested or required in medical examinations related to employment. Such reasonable measures may depend on the facts and circumstances under which a request for genetic information was made, and may include no longer using the services of a health-care professional who continues to request or require genetic information during medical examinations after being informed not to do so.

Health or Genetic Services

The general prohibition against requesting, requiring, or purchasing genetic information does not apply where the School offers health or genetic services, including services offered as part of a voluntary wellness program, if the conditions at 29 CFR 1635.8(b)(2) are met.

The School may not offer a financial inducement for individuals to provide genetic information but may offer financial inducements for completion of health risk assessments that include questions about family medical history or other genetic

information. The School shall make clear, in language reasonably likely to be understood by those completing the health risk assessment, that the inducement will be made available whether or not the participant answers questions regarding genetic information.

The School may offer financial inducements to encourage individuals who have voluntarily provided genetic information (e.g., family medical history) that indicates that they are at increased risk of acquiring a health condition in the future to participate in disease management programs or other programs that promote healthy lifestyles, and/or to meet particular health goals as part of a health or genetic service. However, the School must also offer these programs to individuals with current health conditions and/or to individuals whose lifestyle choices put them at increased risk of developing a condition.

Leave Requests

The general prohibition against requesting, requiring, or purchasing genetic information does not apply where the School requests family medical history to comply with the certification provisions of the FMLA or state or local family and medical leave laws, or pursuant to a policy (even in the absence of requirements of federal, state, or local leave laws) that permits the use of leave to care for a sick family member and that requires all employees to provide information about the health condition of the family member to substantiate the need for leave.

Publicly Available Information

The general prohibition against requesting, requiring, or purchasing genetic information does not apply where the School acquires genetic information from documents that are commercially and publicly available for review or purchase, including newspapers, magazines, periodicals, or books, or through electronic media, such as information communicated through television, movies, or the Internet, except that this exception does not apply to:

1. Medical databases, court records, or research databases available to scientists on a restricted basis;
2. Genetic information acquired through sources with limited access, such as social networking sites and other media sources which require access permission from a specific individual or where access is conditioned on membership in a particular group, unless the School can show that access is routinely granted to all who request it;
3. Genetic information obtained through commercially and publicly available sources if the School sought access to those sources with the intent of obtaining genetic information; or

4. Genetic information obtained through media sources, whether or not commercially and publicly available, if the School is likely to acquire genetic information by accessing those sources, such as Web sites and online discussion groups that focus on issues such as genetic testing of individuals and genetic discrimination.

Workplace Monitoring

The general prohibition against requesting, requiring, or purchasing genetic information does not apply where the School acquires genetic information for use in the genetic monitoring of the biological effects of toxic substances in the workplace. Such monitoring must meet the criteria at 29 CFR 1635.8(b)(5).

Inquiries Made of Family Members

The School does not violate the GINA regulations when it requests, requires, or purchases information about a manifested disease, disorder, or pathological condition of an employee whose family member is also employed by the School or who is receiving health or genetic services on a voluntary basis. For example, the School does not violate the GINA regulations by asking someone whose sister also works for the School to take a post-offer medical examination that does not include requests for genetic information.

Confidentiality

The Superintendent or designee shall maintain genetic information in writing about an employee on forms and in medical files (including where the information exists in electronic forms and files) that are separate from personnel files. The School must treat such information as a confidential medical record. The School may maintain genetic information about an employee in the same file in which it maintains confidential medical information under the ADA.

Genetic information placed in personnel files before November 21, 2009, need not be removed. The School will not be liable under the GINA regulations for the mere existence of the information in the file. However, the prohibitions on use and disclosure of genetic information apply to all genetic information that meets the statutory definition, including genetic information requested, required, or purchased before November 21, 2009.

Genetic information that the School receives orally need not be reduced to writing but may not be disclosed, except as permitted by 29 CFR part 1635.

Genetic information that the School acquires through sources that are commercially and publicly available, as provided by 29 CFR 1635.8(b)(4), is not considered confidential genetic information but may not be used to discriminate against an individual.

Disclosure Permitted

The School may disclose genetic information, regardless of how such information was obtained (except for genetic information acquired through commercially and publicly available sources), as follows:

1. To the employee (or family member if the family member is receiving genetic services) about whom the information pertains upon receipt of the employee's written request;
2. To an occupational or other health researcher if the research is conducted in compliance with the regulations and protections at 45 CFR part 46;
3. In response to an order of a court. The School may disclose only the genetic information expressly authorized by the order. If the order was secured without the knowledge of the employee to whom the information refers, the School shall inform the employee of the order and any genetic information that was disclosed pursuant to the order;
4. To government officials investigating compliance with Title II of GINA if the information is relevant to the investigation;
5. To the extent the information is disclosed in support of an employee's compliance with the certification provisions of the FMLA or certification requirements under state family and medical leave laws; or
6. To a federal, state, or local public health agency, only with regard to information about the manifestation of a disease or disorder that concerns a contagious disease that presents an imminent hazard of death or life-threatening illness, provided that the individual whose family member is the subject of the disclosure is notified of such disclosure.

Relationship to HIPAA Privacy Regulations

The GINA regulations do not apply to the use or disclosure of genetic information that is protected health information subject to regulation under the Health Insurance Portability and Accountability Act of 1996 (HIPAA).