

What is GINA? The federal discrimination law you need to know

GINA, or the Genetic Information Nondiscrimination Act, outlaws genetic discrimination. The federal law has been around for a decade, yet many employers still don't know exactly how to comply. GINA essentially bars using genetic information in employment decisions *and* bars acquiring genetic information improperly.

GINA bars employers from discriminating against or harassing employees based on their genetic information. You cannot acquire or use genetic information except in very limited circumstances. The law also protects employees from employer retaliation. Employers also can't harass or demean employees based on genetic information. If co-workers, for example, find out that a worker or his family member's genetic disorder, any harassment violates GINA.

GINA also prohibits health insurers – including employers who self-insure coverage – from using genetic information to screen out employees for coverage or benefits.

GINA definition

GINA defines genetic information as “information about an individual's genetic tests and the genetic tests of an individual's family members.” It prohibits genetic information employment discrimination. But that's not all. It also outlaws discrimination based on genetic information about the employee's relatives. Courts have interpreted the definition very broadly. For example, employers can't force DNA testing on workers even if the results don't show a genetic disorder.

How do employers acquire genetic information? Possible sources include the results of genetic testing during pregnancy and an employer's access to private medical information through insurance plans. When an employee requests FMLA leave for a serious health condition, the certification form may also reveal a genetic condition. An Americans With Disabilities Act (ADA) request may reveal a genetically-linked disability. Participation in a wellness program may include medical tests that reveal genetics. Or an employee or co-worker may pass on information about an inherited condition.

Genetic discrimination examples

Employers that won't hire or who fire employees in part because of genetic information violate GINA's genetic discrimination provisions. Employers that try to obtain genetic information by demanding testing also violate GINA. Remember that how much an employee with a genetic disorder will cost the employer in health costs is irrelevant. That's also true if a family member's genetically linked condition will mean expensive treatment or prescriptions. Here are some examples.

- An employer received complaints from supervisors that someone was defecating in the warehouse. The supervisor suspected two warehouse workers and told them to submit to DNA testing or face discharge. The men agreed to a cheek swab test for DNA. That test showed they were not the defecation culprits. The men sued, alleging that the demand for genetic information violated GINA. A jury awarded them

\$2.25 million. (*Lowe, et al., v. Atlas Logistics*, 1:13-CV-2425, ND GA 2019)

- An employee's wife and two children have a rare genetic condition that causes excruciating pain in their bones. It is a so-called orphan disease that affects very few individuals. There is a treatment, but the newly developed drug costs about \$6 million per year. The employer has a generous health plan that covers the prescription. However, the high cost means increasing premiums. The employer can only make changes to the health plan consistent with the Affordable Care Act (ACA). It can terminate the health plan entirely and face ACA penalties. It can change the deductible and premium payments for *all*. Or it can keep paying. But it can't fire the employee to save money or force her to pay more unless everyone has to. Terminating the employee to save costs associated with the drug is genetic discrimination and illegal under GINA.
- An applicant volunteered during an interview that she carries a gene that makes it more likely she will develop cancer. The hiring manager doesn't recommend her hiring, mentioning both her potential impact on health insurance costs. The company already struggles to provide coverage because several employees have recently had medical challenges. Recommending against her hire based on her potential future cost is genetic discrimination under GINA.
- A supervisor hears that his subordinate has a gene that makes it more likely the subordinate will have a heart attack. Based on his assumption that stress causes heart attacks, the supervisor refuses to recommend a promotion to a stressful job. This is genetic discrimination under GINA.

Genetic testing

Back when GINA was written, genetic tests were expensive and complicated. They were anything but routine. Individuals who suspected a family history of genetic abnormalities like Tay Sachs, Muscular Dystrophy or Sickle-cell might request testing. If the results were positive for a suspected genetic disorder, they might have sought genetic counseling or have foregone pregnancy.

That's all changed in the span of a decade. Today, your employees can order a comprehensive DNA test for \$59, spit in a tube and wait for the results. Ancestry and 23andMe are just two of the services that sell tests. Tests are typically sold as a way to determine ancestry and create a family tree. Some companies provide a report on genes linked to inheritable conditions. In addition, all major DNA testing services also allow customers to download raw DNA data. They can then load that data into several databases, including some that evaluate specific disorder risks.

Your employees may have a good idea of their chances of coming down with diabetes, heart disease or cancer. They may share that information with co-workers and supervisors. It's just one of many ways your organization may come across protected genetic information. Acting on that information is prohibited genetic discrimination under GINA's expansive definition. Don't use genetic information to make adverse employment decisions no matter how you came across the data. Employers who overhear or accidentally find out an employee's genetic information may not use that information against the employee.

Acquiring GINA information

The Equal Employment Opportunity Commission (EEOC) is charged with enforcing GINA's genetic discrimination provisions. It says that employers don't violate GINA when genetic information comes to it innocently. Of course, employers can't then use the acquired information against the employee. These are some ways employers acquire genetic information:

- The employer doesn't ask for, but receives genetic information inadvertently.
- Family medical history that's genetically based is included on certification forms for FMLA or other leave or ADA accommodation requests.
- Genetic information is acquired through commercially and publicly available documents like newspapers or genealogy websites. The employer didn't go looking for the information.

- Genetic information is acquired during a genetic monitoring program that monitors the biological effects of toxic substances in the workplace.

GINA safe harbor rule

GINA regulations provide employers with a “safe harbor” for collecting genetic information. For example, FMLA leave or ADA reasonable accommodation requests could mean receiving genetic information. When requesting medical information from medical professionals include the following statement:

The Genetic Information Nondisclosure 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.

This safe harbor language should also be on all requests for employee medical information such as for fitness-for-duty determinations.

Storing genetic information

Employers must keep genetic information about applicants and employees confidential. Written genetic information must keep it apart from other personnel information in separate medical files. Employers may only disclose genetic information:

- To the employee or family member on employee's or family member's written request;
- To an occupational or other health researcher conducting research under federal regulations;
- In response to a court order specifically requesting the information;
- To government officials investigating GINA compliance;
- When handling FMLA leave or state family and medical leave law requests;
- To a public health agency if the information concerns a contagious disease that’s an imminent hazard to health or life-threatening illness.

GINA and wellness programs

Both GINA and the ADA allow employers to gather health information as long as the information is provided “voluntarily.” EEOC regulations issued in 2016 allowed employers to offer incentives to participate in the programs. The regulations allowed employers to provide incentives as much as 30% of employee healthcare costs.

A court challenge argued the 30% figure amounted to a penalty for not participating. As a result, participation was not voluntary in any real sense. A federal district court vacated the rules as of January 1, 2018. Currently, no rules exist on this matter. The EEOC promised the court it would issue new rules in October 2019. Stay tuned.