

Genetic discrimination

Genetic Information Nondiscrimination Act (GINA)

The Genetic Information Nondiscrimination Act (GINA) [Public Law 110-233] protects individuals from genetic discrimination by health insurers and employers.

GINA Title I protections

Title I of GINA prohibits group and individual health insurers from using a person's genetic information to determine eligibility or premiums. It also prohibits health insurers from requesting or requiring that a person undergo a genetic test in order to collect genetic information for underwriting decisions.

GINA Title II protections

Title II of GINA prohibits employers from using a person's genetic information in making employment decisions such as hiring, firing, job assignments or any other terms of employment. It also prohibits employers from requesting, requiring or purchasing genetic information about a person or their family members.

Gaps in GINA

The AMA believes patient care is negatively impacted by fear of genetic discrimination. While GINA provides some important protections, the AMA's Council on Science and Public Health recently examined GINA and identified some gaps.

Report 7 of the Council on Science and Public Health (A-13) (PDF)

Among the council's findings are:

- GINA leaves individuals vulnerable to discrimination in areas such as life, long-term care and disability insurance, and does not extend to certain sectors of the population.
- Many health care providers and patients are not aware of current protections against genetic discrimination, suggesting that educational efforts are warranted.

In addition, the AMA developed a policy perspective on GINA calling for improvements in laws that protect individuals from discrimination and also stating that:

Genetic discrimination, June 2013 (PDF)

- | Genetic information should be kept confidential and should not be disclosed to third parties without the explicit informed consent of the tested individual.
- | The AMA Board of Trustees is directed to monitor and support federal legislation that will afford patients protection against genetic discrimination.

Additional anti discrimination protection

Federal legislation

The first federal law to address genetic discrimination was the Health Insurance Portability and Accountability Act (HIPAA) of 1996. The Americans with Disabilities Act (ADA) prohibits employment discrimination based on a disability; however, it is not clear whether the ADA protects against genetic discrimination in employment decisions.

State legislation

Fewer than half of U.S. states have laws that provide additional protection against areas that are not in GINA. Some states have developed regulations concerning genetic nondiscrimination in employment and insurance, health insurance coverage, genetic privacy and research.

Executive order

In February 2000, President Clinton banned genetic discrimination when he issued Executive Order 13145, which prohibits discrimination against any federal employee. Similarly, internal policies of the U.S. military and the Veteran's Health Administration afford protections similar to GINA.

Find more information about other personalized medicine advocacy topics.