

The Genetic Information Nondiscrimination Act of 2008 (GINA) provides federal safeguards to prohibit employer or insurance discrimination based on personal or familial genetic information or conditions. Awareness of the implications of genetic testing in individuals and families and of state and federal legislation in place for their protection is an essential component of oncology nursing practice. This article discusses the critical role of the oncology nurse in interacting with and providing information about GINA to patients in a cancer care setting engaged in genetic assessment.

#### AT A GLANCE

- GINA protects individuals against workplace or insurance discrimination connected to genetic information in an individual or family. The law does not cover military, life, long-term, or disability insurance.
- States have laws that protect individuals' and families' genetic information, and practitioners should be aware of protections unique to the patient population served.
- Informed and engaged oncology nurses should participate in interprofessional teams to learn how to interpret and apply genetic information in practice and research.

#### KEYWORDS

Genetic Information Nondiscrimination Act; genetic testing; genetic discrimination

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# Genetic Discrimination

## The Genetic Information Nondiscrimination Act's impact on practice and research

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Genetic testing and risk assessment are now a standard part of care of the patient with cancer, as well as a large component of current research initiatives. Genetic information has implications across the spectrum of care, ranging from identifying risk for cancer in unaffected individuals to targeting treatment in those with cancer. Genetic information can be identified through testing or family history assessment. In response to public concerns about future genetic discrimination related to the Human Genome Project, a federal law was passed to provide workplace and insurance protections for individuals related to genetic information: the Genetic Information Nondiscrimination Act of 2008 (GINA).

GINA protects an individual's genetic information, including family history and/or genetic testing results, in the workplace and in regard to health insurance. GINA is one of several federal laws that protect against genetic discrimination, including the Americans with Disabilities Act of 1990, the Health Insurance Portability and Accountability Act of 1996, and the Patient Protection and Affordable Care Act of 2010 (ACA). The ACA provisions related to pre-existing conditions are important because GINA has a limited impact on patients who already have a diagnosis of cancer; GINA is focused largely on protection against discrimination related to risk for future disease, not when disease has already occurred. Under GINA, genetic information

is considered broadly and includes genetic tests, both those done through direct-to-consumer testing as well as those ordered clinically by a healthcare provider, and results, family medical history, and use of genetic services (Areheart & Roberts, 2019; Flynn, 2019; Steck & Hassen, 2019).

In terms of workplace-related provisions, GINA denies employers the right to ask for genetic information or to use this information to make employment decisions; this provision applies to workplaces with 15 or more employees. In relation to insurance protections, insurance companies cannot ask for or sell genetic information and are prohibited from raising insurance premiums based on this information. However, health insurers can request genetic information when making payment decisions. Protection does not include life, long-term, or disability insurance. In addition, members of the U.S. military who receive health care through government- or military-sponsored health insurance providers are not protected. GINA is a federal law that provides a baseline level of protection for individuals' genetic information. State laws are also in place to protect against genetic discrimination and vary from state to state. In some cases, state laws offer more protections on top of GINA (Areheart & Roberts, 2019; Flynn, 2019; Steck & Hassen, 2019).

#### Implications for Practice

Oncology nurses advocate for patients to be fully informed about the cancer care