



The Genetic Information Nondiscrimination Act

President Bush signed the Genetic Information Nondiscrimination Act (GINA) of 2008 into law on May 21, 2008. The law makes it illegal for health insurers or employers to discriminate against individuals based on their genetic information. All provisions of the law will take effect within 18 months of the signing.

Genetic testing has grown dramatically in the past decade, and increasingly is becoming an integral part of health care. Genetic tests can help diagnose genetic conditions and guide treatment decisions, help predict risk of future disease, inform reproductive decision making, and assist medication selection or dosing.

For many years, patients who might have benefited from genetic testing avoided it – or obtained it anonymously or under assumed names – out of concern about possible repercussions. Until GINA takes effect, individuals' genetic information is protected only by a patchwork of state and federal regulations. In a poll conducted in 2007 by the Genetics and Public Policy Center, 93 percent of Americans stated that health insurers and employers should not be able to use such information.

GINA's passage should reassure individuals who have been hesitant to take advantage of genetic tests -- tests that are now available clinically for approximately 1200 diseases. Finally, Americans no longer have to make trade-offs between guarding their genetic privacy and benefiting from appropriate health care, such as monitoring and preventive care, based on their genetic susceptibility to disease.

GINA prevents health insurers from denying coverage, adjusting premiums on the basis of genetic information, or requesting that an individual undergo a genetic test. Similarly, employers are prohibited from using genetic information to make hiring, firing, or promotion decisions. The law also sharply limits an employer's right to request, require, or purchase an employee's genetic information.

GINA benefits genetic research as well as individuals. Linking gene variants to health outcomes often requires studies involving large numbers of people, but scientists long have reported that potential research participants have been deterred by fears that their information could be used against them by employers and insurers. Now scientists can assure study participants that neither their participation in a research study nor their genetic information legally can be used against them by their employers or health insurers.

When people opt not to be tested, they lose the opportunity to seek monitoring and preventive care to avoid conditions for which they are at heightened risk. Thus fear of genetic discrimination also affects health insurers (who must pay more to treat conditions that are not prevented or caught early) and employers (who bear the economic costs if employees require more sick days and medical leave).

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