Policy in Focus

The Genetic Information Nondiscrimination Act: A First Step Toward Protecting Americans From Misuse of Genetic Information

President George W. Bush signed the Genetic Information Nondiscrimination Act (GINA) into law on May 21, 2008, with the explanation that "it protects our citizens from having genetic information misused, and this bill does so without undermining the basic premise of the insurance industry." At the bill signing ceremony, President Bush also offered a special thank you to Senator Ted Kennedy for more than a decade of work on the legislation.

Advocates for the new law heralded their success, achieved after 13 years of hard work to secure serious consideration and passage. Proponents of the new law believe it will offer substantial protection against discrimination on the basis of genetic information in issuance or premium setting in health insurance as well as protection against discrimination in employment. The law will eliminate concerns among Americans about the ramifications of seeking genetic testing and counseling, and will also foster aggressive efforts to develop and disseminate new genetic tests. Supporters of the new law believe that its passage sets the stage for more rapid progress toward an era of personalized medicine.

GINA defines genetic information as an individual's genetic tests, the genetic tests of family members (up to fourth-degree relatives), a manifestation of disease in a family member, or participation of an individual or family member in research that includes genetic testing.

The health insurance provisions of GINA will go into effect 12 months after enactment, with the employment provisions following 6 months later, or 18 months after enactment.

What Does GINA Do?

GINA will:

- Prohibit group and individual health insurers from using an individual's genetic information to determine eligibility for insurance or premiums for insurance;
- Block an insurer from requesting or requiring an individual to take a genetic test;
- Prohibit employers from using genetic information in making decisions related to hiring, firing, or other terms of employment;
- Prevent employers from requesting, requiring, or purchasing genetic information about employees or their family members.

What Won't GINA Do?

GINA does not mandate coverage for any particular genetic test, nor does it require coverage for any treatment. Although the law would prevent underwriting on the basis of genetic information, it would not prevent medical underwriting on the basis of current health condition. Neither would the law cover life, disability, or long-term care insurance.

The new law will not prevent health care providers from recommending genetic tests to their patients. In fact, its supporters believe that providers will be more aggressive in recommending tests if they can assure their patients that they are protected from discrimination based on the genetic information that might result from testing.

Are There Any Shortcomings to GINA?

Critics of the law have suggested that GINA underscores the limits of an incremental approach to health care reform and note that GINA would provide an individual with a family history of cancer or an increased genetic risk of cancer insurance protection, while offering no similar protection to one already diagnosed with cancer. For these critics, the solution is elimination of medical underwriting.

Champions of GINA concluded that comprehensive insurance reform, which would have included elimination of medical underwriting, was not a realistic possibility when GINA was introduced. In the face of that challenge, they made a conscious and deliberate decision to pursue an achievable goal—the protections offered by GINA—a goal that nonetheless took 13 years to achieve. Some also note that GINA does not address the additional regulatory issues related to genetic testing, including the need for greater oversight to ensure the quality and reliability of genetic tests. These regulatory steps are considered important to ensure that genetic tests are reliable, affordable, and used broadly in connection with genetic counseling to improve the quality of health care.

Conclusion

Those who began the fight for a genetic nondiscrimination law more than a decade ago have remained steadfast in their support of the effort and in their belief that it will provide meaningful protections to Americans in a genomic age. The Coalition for Genetic Fairness, a key player in enactment of the legislation, remains dedicated to smooth implementation of the law. The Coalition describes the law as the first civil rights law of the new millennium and offers materials to guarantee adherence to the new law at http://www.geneticfairness.org/.

DOI: 10.1200/JOP.0912504

* * *