Getting to Know GINA: An Overview of the Genetic Information Nondiscrimination Act

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by Don Asmonga, MBA

After 13 years of advocacy, the Genetic Information Nondiscrimination Act (HR 493), or GINA, finally passed both houses of Congress with strong bipartisan effort.

AHIMA and the sponsors of the legislation have travelled a long and winding road to pass this important act that prohibits both insurers and employers from discriminating against individuals on the basis of their genetic make-up.

Title I: Preventing Insurance Discrimination

The first thing GINA does is to amend the Employee Retirement Income Security Act, the Public Health Service Act, and the Internal Revenue Code to prohibit group health plans, individual insurers, and Medicare supplemental policies from adjusting premiums or contribution amounts for a group on the basis of genetic information.

In addition, the first title of the act establishes a prohibition on group health plans from requesting or requiring individuals or family members from undergoing a genetic test.

The prohibition contains some exceptions. It does not limit the authority of a healthcare professional to request an individual to undergo a genetic test or preclude a group health plan from obtaining or using the results of a genetic test in making a determination regarding payment.

The legislation also enables a group health plan to request that a participant or beneficiary take a genetic test for research if certain requirements are met, including:

- It is clearly indicated by the plan that compliance is voluntary and noncompliance will have no effect on enrollment status, premium, or contribution amounts
- Any genetic information collected or acquired cannot be used for underwriting purposes
- The plan notifies and describes its activity to the Health and Human Services secretary that it is conducting activities within this exception

Finally, GINA prohibits a group health plan from requesting, requiring, or purchasing genetic information for underwriting purposes or with respect to any individual prior to such individual's enrollment in a plan.

GINA's amendment of the Public Health Service Act addresses the individual insurance market (nongovernmental plans) in much the same manner that it addresses the group insurance market. In addition, it prohibits a health insurance issuer offering coverage in the individual market from establishing eligibility rules based on genetic information. Health insurance issuers offering coverage are also prohibited from imposing a preexisting condition exclusion on the basis of genetic information.

Medicare supplemental policies are also addressed by way of amending the Social Security Act. GINA prohibits issuers of Medicare supplemental policies from:

- Denying or conditioning the issuance or effectiveness of the supplemental policy, including the imposition of any exclusion of benefits, based on a preexisting condition
- Discriminating in the pricing of the policy, including the adjustment of premium rates
- Requesting or requiring an individual or family member to undergo a genetic test
- Requesting, requiring, or purchasing genetic information for underwriting purposes or for any individual prior to enrollment

Finally, the remaining legislative language in the first title of GINA serves more of a federal regulatory and administrative coordination function. First, the language calls on the Health and Human Services secretary to revise the HIPAA privacy regulations to ensure the treatment of genetic information as health information under HIPAA and to prohibit the use and disclosure by a group health plan, health insurance coverage, or Medicare supplemental policy of genetic information about an individual for underwriting purposes.

Additionally, the language requires the adoption of a coordinated enforcement and interpretation strategy by the Health and Human Services secretary, the Secretary of Labor, and the Treasury Secretary.

GINA's Long Legislative Road

It took years to get the Genetic Information Nondiscrimination Act introduced into Congress, and it took years to get an approved version back out again.

In January 2007 Rep. Louise Slaughter (D-NY) introduced the act into Congress, as she had in previous years. The act's goal was to ban insurers and employers from discriminating against individuals on the basis of their genetic make-up. With 224 cosponsors, the bill had strong bipartisan support prior to its consideration on the House floor.

This support was critical, because the legislation had applications to insurance and employment. This meant it had to traverse through three separate House committees: the House Ways and Means Committee, the House Energy and Commerce Committee, and the House Education and Labor Committee. In February and March, each committee passed GINA by voice vote, and on April 25, 2007, the full House passed GINA by an overwhelming vote of 420–3.

Senate consideration was more difficult than it had been in previous Congresses. In past years the Senate was the first body to pass GINA. It would then send the act to the House, where the act would eventually get snagged in political battles and languish without consideration.

In 2007 Sen. Olympia Snowe (R-ME) introduced GINA in the Senate (S. 358) and garnered 45 bipartisan cosponsors. Sen. Edward M. Kennedy (D-MA), chair of the Senate Health, Education, Labor and Pensions Committee, quickly shepherded the legislation through that committee on March 29, 2007. Unfortunately, several issues held the bill from moving forward, and a breakthrough took longer than a year to achieve.

Finally, in 2008, the Senate took the version of GINA passed by the House, made minor modifications to the legislative language, and passed it 95–0 on April 24, 2008. The House agreed to the Senate modifications by a vote of 414–1. After 13 long years, GINA cleared Congress and made its way to the president, who signed it into law on May 21, 2008.

Title II: Preventing Employment Discrimination

Title II addresses employment discrimination. GINA explicitly prohibits and makes unlawful the discrimination by an employer, employment agency, labor organization, or joint labor-management committee against an employee, individual, or member because of genetic information. The prescriptive prohibitions include the following:

- An employer is prohibited from failing to hire or discharge an employee or otherwise discriminate against an employee with respect to the compensation, terms, conditions, or privileges of employment on the basis of genetic make-up.
- An employment agency is prohibited from failing or refusing to refer an individual for employment on the basis of genetic make-up.
- A labor organization is prohibited from excluding or expelling a member from the organization on the basis of genetic make-up.
- An employment agency, labor organization, or joint labor-management committee is prohibited from causing or attempting to cause an employer to discriminate against a member in violation of this act.

- An employer, labor organization, or joint labor-management committee is prohibited from discriminating against an individual in admission to, or employment in, any program established to provide apprenticeships or other training or retraining.

These employment and labor groups are prohibited from limiting, segregating, or classifying employees, individuals, or members because of genetic information in any way that would deprive or tend to deprive them of employment opportunities or otherwise adversely affect their status as employees.

Also unlawful under the act is the employment practice of requesting, requiring, or purchasing an employee's genetic information. The information can only be requested when:

- The information is requested or required to comply with certification requirements of family and medical leave laws
- The information involved is to be used for genetic monitoring of the biological effects of toxic substances in the workplace
- The employer conducts DNA analysis for law enforcement purposes as a forensic laboratory

GINA also has a separate file requirement for employers, employment agencies, labor organizations, and joint labor-management committees. If any possess genetic information about an employee or member of the organization, the information must be maintained in separate files and treated as a confidential medical record. This information may only be disclosed:

- To the employee or member upon request
- To an occupational or other health researcher
- In response to a court order
- To a government official investigating compliance with this act if the information is relevant to the investigation
- In connection with the employee's compliance with the certification provisions of the Family and Medical Leave Act of 1993 or such requirements under state family and medical leave laws
- To a public health agency

Under this section GINA also establishes the Genetic Nondiscrimination Study Commission to review the "developing science of genetics and make recommendations to Congress regarding whether to provide a disparate impact cause of action under GINA." The commission would not be created until six years after GINA enactment, and the Equal Employment Opportunity Commission would receive any appropriations to carry out these provisions.

According to the National Human Genome Research Project, GINA will be added to the list of the Americans with Disabilities Act of 1990, HIPAA, the HIPAA privacy rule, and Title VII of the Civil Rights Act of 1964 as a federal antidiscrimination law that deals with genetics.

Now that this legislation has been signed into law, the respective federal agencies affected by GINA are required to draft regulations pertaining to their requirements under this act. As those regulations are produced, AHIMA will review and comment and also provide members with any specific steps necessary to prepare for implementation of GINA.

The text of GINA is available in the Action Center of the AHIMA Advocacy Assistant at https://secure.ahima.org/DC/Login.asp.

Collins to Depart National Human Genome Research Institute

Francis S. Collins, MD, PhD, the director of the National Human Genome Research Institute (NHGRI), announced his intention to leave NHGRI on August 1 to explore new opportunities. Collins has served as director since 1993 and oversaw the completion of the Human Genome Project—the mapping of the human genome—in 2003.

AHIMA members may remember a memorable presentation by Collins at the AHIMA National Convention and Exhibit in Washington, DC, in October 2004. One international attendee remarked, "I traveled all the way from

Australia for this convention, but if his presentation had been the only thing I heard, it would have been worth the trip."

Understanding the importance and power of genetic information, Collins has consistently demonstrated awareness of the ethical, legal, and social implications of genetic research. In addition, he has been a strong supporter of passing genetic information nondiscrimination legislation throughout his years at the NHGRI. Without Collins' outspoken support for the Genetic Information Nondiscrimination Act, it is highly unlikely that it would have ever become law.

Collins' biography may be read at www.genome.gov/ 10000779.

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