GINA makes it unlawful for an employer “to fail or refuse to hire, or to discharge, any employee, or otherwise to discriminate against any employee with respect to the compensation, terms, conditions of employment of the employee because of genetic information with respect to the employee.” It further makes it unlawful “to limit, segregate, or classify the employees of an employer in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the status of the employee as an employee because of genetic information with respect to the employee.”

The act includes employment agencies, labor organizations and training programs in the nondiscrimination provisions, and also makes acquisition of genetic information unlawful, with certain specific exceptions. There are further obligations set forth in the act related to the confidentiality and disclosure of genetic information.  

To some, GINA may simply be a new...
entry into the “alphabet soup” of statutes governing employment in the United States, or another administrative burden and another set of potential legal liabilities for employers. There is, however, a web of legal, social and scientific influences behind the act that provide a noteworthy historical perspective on genetic testing. Looking forward, the potential interactions of GINA with various other statutes, including the Americans with Disabilities Act (ADA), and the Family and Medical Leave Act (FMLA), will present interesting challenges. It may be that a new “Bermuda Triangle” is in the making, the catchphrase given to the sometimes complex overlap of the ADA, FMLA, and Workers’ Compensation statutes.

Potential complications in the application of the act are reviewed here, preceded by a survey of historical reference points leading to its enactment.

History of the Act

Was GINA simply a successful democratic movement in Congress to add more employee protections in the workplace? Hardly. In 2007 the House passed the bill by a vote of 420 to 3, and in 2008 the Senate did so by 95 to 0. Was it a recently contrived attempt to make government seem ahead of the scientific curve by legislating the use of genetic information? Again, hardly. GINA has been at least 13 years in the making, being first introduced in 1995.

In her remarks to Congress in support of GINA in 2007 Senator Olympia J. Snowe, R-Maine, described this as an action to “prevent discrimination before it has taken firm hold.... For in the past Congress has had to act to address existing discrimination. But today we are acting proactively to address genetic bias, before discrimination becomes entrenched.”

To the extent that these comments were interpreted to suggest that genetic bias had not yet occurred, quite the opposite is true. Rather, dramatic events have taken place over the last century that have a rightful place in the history of genetic testing laws.

In an introduction to the text of the act, the drafters noted an example of genetic discrimination as far back as 1907, when the State of Indiana enacted a law that called for the “sterilization” of persons who were thought to have genetic defects such as mental disease, epilepsy, blindness, etc. Similar state laws followed, later to be rescinded or modified. The discovery of DNA came in 1953, and at about that same time soldiers in the Korean War who were carriers of a glucose deficiency were becoming afflicted by hemolysis, a blood disease. “Preplacement” genetic exams could have led to avoidance of exposure to chemicals and drugs which caused the soldiers’ illnesses.

In 1970, concerns over sickle cell anemia, a condition mainly affecting African-Americans, resulted in widespread efforts to identify carriers of the disease. This soon led to discrimination.

Violations of GINA may also be construed as violations of the FMLA and/or the ADA, and even related state laws, depending on the facts of each case. The result may be multiple and overlapping claims, and extensive analysis of the appropriate interaction among the various statutes.

which soon led to the National Sickle Cell Anemia Control Act in 1972, which withheld funds from any state requiring involuntary sickle cell testing.

The actions of the Lawrence Berkeley Laboratory and the Burlington Northern Santa Fe Railway Corporation in the 1990s, in conducting genetic testing of employees, led to lawsuits which were referenced frequently in congressional debates as examples of abuses that required the protections for employees offered by GINA. In Norman-Bloodsaw v. Lawrence Berkeley Laboratory, employees of the Laboratory alleged that they were subjected to mandatory pre-employment examinations which, without their knowledge, tested for such conditions as syphilis, sickle cell trait and pregnancy.

The Equal Employment Opportunity Commission (EEOC) sued Burlington Northern in 2001 alleging the same type of unauthorized genetic testing on employees, in this case purportedly done to find the cause of their carpal tunnel syndrome, which had resulted in Workers’ Compensation claims. The relevant portion of the Norman-Bloodsaw case was dismissed, and Burlington Northern settled prior to trial for $2.2 million.

In the midst of these more recent events, the Human Genome Project, an international effort by scientists to map and sequence human chromosomes, was making history, so much so that it was compared to “the Apollo Program bringing humanity to the moon.”

In his remarks during the House debate in 2007, Representative George Miller stated that “[t]he Human Genome Project started the revolution in science and medicine nearly 20 years ago by identifying the specific chromosomes within the genes that make up the human body. Once the scientists identified and understood these genetic building blocks, they developed tests that identified genetic markers for diseases that could, but may never, occur. We understand that this scientific revolution can and will save lives. It can save children from devastating illnesses, and once these tests and treatments become more widely available, they will help us live longer lives with less debilitating diseases.”

Mr. Miller followed these remarks with a caution that persons undergoing genetic testing and counseling must be protected from discrimination and invasion of their privacy in the process.

Thus, 100 years after the State of Indiana began sterilizing citizens it considered risks for future medical problems, GINA was enacted. An April 2008 report on this topic declared that “[t]he world stands on the brink of a genome-based personalized-medicine revolution, with individual Americans poised to be the greatest beneficiaries.”

With this information available, however, barriers to its usefulness have developed based in part on fear of discrimination in employment and in health care. Patients are reportedly forgoing tests that could preserve or prolong their lives. Moreover, there is a concern that the boundaries of further scientific research are being limited by the reluctance of individuals to participate in studies. Senator Snowe described this time as the “threshold of a new era,” and her warning was not that discrimination did not exist but that there is a need to “address genetic bias, before discrimination becomes entrenched.”

GINA is intended to do just that.

The Application of the Act

GINA becomes effective in November 2009, entering the current array of employment discrimination laws, and overlapping with
some of them. A simple hypothetical suggests some of the possibilities: An employee’s father is seriously ill, and the employee asks for FMLA leave to care for him. In this case, the employee’s father has a genetic component and the employee is likely to develop the disability as well…”

The ADA provision played no part in the Larimer decision, although the court’s reference to a “genetic component” certainly would now implicate GINA. The Seventh Circuit’s ADA analysis was repeated in subsequent cases; however, the genetic component factor played no role in the decisions.

ADA association discrimination based on genetic predisposition has been cited only in dicta in the above cases, and the applicability of this provision remains an open issue.

The second potential ADA claim arises from the “regarded as” provision. The ADA protects employees who are disabled, as defined by the statute, “perceived” to be disabled, or “regarded” as disabled. The EEOC Compliance Manual sets forth a definition of “disability” which includes discrimination based on genetic information where an employee “has no impairment but is regarded as having a substantially limiting impairment.”

In an explanatory hypothetical, the EEOC posited a situation in which a job offer is rescinded when the employer becomes aware of a genetic profile revealing the applicant’s increased susceptibility to colon cancer. This guidance has yet to find support in the case law, leaving this ADA application an open issue as well.

Many state laws on genetic testing also exist, although they have been referred to as a “patchwork…offering different levels and forms of protection.”

An amendment to the New York Human Rights Law (HRL) became effective in 1996 which parallels the protections set forth in GINA.

The amendment pointed to concerns that otherwise healthy individuals would be labeled genetically “defective,” potentially resulting in a “genetic underclass of society.”

While this law has had scarce application since that time, the New York Yankees did manage their way into the record books. The Yankees were sued in 2003 in a case in which the plaintiff alleged, inter alia, that his discharge was related in part to his HIV-positive status.

In dismissing this aspect of the lawsuit under the HRL, the Appellate Division, First Department, noted that §296(1)(a) “prohibits discrimination based, inter alia, on ‘genetic predisposition or carrier status.’” Plaintiff in this case struck out, however, based on his failure to satisfy his burden of proof. Specifically, to establish the claim that his own doctors disclosed his condition to team doctors, the plaintiff could only suggest that this was so because “doctors do confer with each other.”

Violations of GINA may also be construed as violations of the FMLA and/or the ADA, and even related state laws, depending on the facts of each case. The result may be multiple and overlapping claims, and extensive analysis of the appropriate interaction among the various statutes. The “Bermuda Triangle” may be duplicated, and may even take on larger geometric proportions.

10. Id. at 1273-74; Molly McDonough, “EEOC Reaches $2.2 Million Settlement With Railroad,” 1 No. 21 A.B.A.J. E-Report (May 31, 2002).