



NEW GENETIC DISCRIMINATION LAW REFLECTS FUTURISTIC CHALLENGES FOR HR PROFESSION

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Genetics are what make people unique. Unfortunately, within our genetic makeup are genes which we can now safely predict will cause us to experience certain diseases and illnesses during our lifetimes. This predictability has led to advances in genetic technology. Genetic tests are now available for 1,200 diseases, and tests for hundreds of others are currently being developed. According to the National Human Genome Research Institute, almost everyone has at least six genetic mutations placing them at greater risk for some disease. Having a genetic mutation does not mean that the disease will develop but it does reflect an elevated risk.

As with other biotechnological breakthroughs, legal and ethical concerns have arisen. For example, is it lawful for employers to use genetic testing for hiring or promotion decisions? May insurers deny coverage, or charge higher premiums, to an individual (or to a group health plan) that, according to their genetic profile, is at higher risk for certain diseases?

Some of these concerns are based on actual historical practices. For example, in the 1970s, some insurance companies began denying coverage to African Americans who carried the sickle cell anemia gene. Also, in some instances young children have been denied health insurance because they carried a recessive genetic disease. More recently, some employers began using the genetic technology to test for genetic predispositions to carpal tunnel syndrome. The largest concern, however, was the fear of future technology, and how that technology, applied to genetic make-ups, could result in larger numbers of unemployed and uninsured individuals. Conversely, because the technology is new, and its benefits largely untested, there have been relatively few who have defended the technology against these concerns.

States were the first to begin passing laws restricting or banning the use of genetic technology in the workplace and in relation to health insurance decisions. Wisconsin was the first to adopt a state law, in 1991, as an amendment to the Fair Employment Act which, with few exceptions, prohibited the use of genetic testing in the workplace. Still, public concerns about the possible future use of genetic testing continued to rise. Finally, on May 21, 2008, President Bush signed the Genetic Information Nondiscrimination Act (“GINA”) into federal law. Some have referred to GINA as the

“First Civil Rights Legislation of the New Millennium”.

GINA’s prohibitions on genetic testing and use of genetic information have two primary focuses: health insurance coverage and employment decisions. The health insurance provisions become effective on May 21, 2009 and the employer provisions on November 21, 2009.

The employment-related provisions will be fairly consistent with the existing Wisconsin law covering Wisconsin employers, but will now cover facilities and employees throughout the country. Under GINA, employers with fifteen or more employees are prohibited from discriminating against an individual in the hiring, firing, compensation, terms, or privileges of employment on the basis of genetic information of the individual or one of their family members. A family member includes a spouse, dependant child, parent, grandparent or great-grandparent. Further, employers must keep any genetic information strictly confidential in compliance with the ADA and the HIPAA medical privacy laws. GINA also makes it unlawful for an employer to request, require or purchase genetic information about an employee or applicant. The penalties for violations are severe, and violations could be punished under both state and federal law.

On the health insurance side, GINA expands current restrictions on the use of genetic information in health insurance ratings, coverages, and exclusions. While HIPAA has prohibited health insurers from using genetic information in deciding whether to insure an individual, GINA will now prohibits group health insurance plans and self insured employers companies from requiring plan participants to undergo genetic testing, or from using genetic information to set premiums or determine enrollment eligibility.

One area that will remain a topic of discussion will be the use of genetic information in wellness plans. Interestingly, GINA specifically excepts genetic testing which is conducted as part of a voluntary wellness plan that is otherwise compliant with HIPAA and ADA requirements. The wellness plan exception is very narrowly crafted, and it is anticipated that further clarification might be provided from federal agencies on this issue, given the ever-increasing use of wellness plans by U.S. employers. In addition, Wisconsin law currently does not contain a similar express exception for wellness plans, so Wisconsin employers will have to evaluate the application of the existing state law to any efforts to include genetic testing as part of a wellness program. At a minimum, strict security measures will need to be applied to any genetic testing information in the possession of the employer.

Certainly there are legitimate arguments to support the use of genetic testing in specific circumstances. If in fact the testing can identify likely medical risks to individuals, it

could be of great benefit to those individuals, and perhaps cause the individual to engage in life-saving or life-extending actions. This would certainly benefit the individual, the employer and the insurer. At the same time, the current “phobias” of the possible misuse of this information, and fear of how far future technology could go in analyzing genetic information, continues to act as a deterrent to even helpful uses of this technology.

GINA has other exceptions that may open the door for some limited beneficial uses, although it is not clear how these exceptions, like wellness exception, will be able to be used by employers, particularly in states like Wisconsin with state law restrictions. Many of the exceptions were created because of the broad definition of “genetic information.” First, employers are allowed to possess materials that are “commercially available” which may contain genetic-related information. Also, employers may receive genetic information from employees as part of a medical certification under the Family and Medical Leave Act. Also, GINA permits genetic monitoring of possible biological effects of toxic substances in the workplace. Each of these exceptions may face prohibitions under corresponding state law, so HR professionals will need to be extremely cautious before pursuing genetic information under any of these exceptions.

In summary, much uncertainty exists with respect to the future application of the “Civil Rights Law of the New Millennium”. Hopefully, employers and insurers will be able to take advantage of the useful aspects of genetic information in the future without negatively impacting employability or insurability. However, because of concerns over those issues, and heightened concerns over medical privacy, HR professionals should be extremely cautious when possessing, using or evaluating any form of genetic information or testing. Additional information on this new law is available through the authors.