


# Genetic Discrimination in Employment

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On May 21, 2008, President Bush signed the Genetic Information Nondiscrimination Act of 2008 (GINA).<sup>1</sup> Effective November 21, 2009, the law prohibits genetic discrimination in both the health insurance and employment settings and limits access to and disclosure of genetic information. The Equal Employment Opportunity Commission (EEOC) will enforce the law and has 12 months within which to issue final regulations. Although both houses of Congress passed GINA with almost unanimous bilateral support, critics have questioned both the need for and the potential effectiveness of the act.

## The Genetic Information Nondiscrimination Act of 2008

GINA covers employers with more than 15 employees and, in language modeled after Title VII of the Civil Rights Act of 1964,<sup>2</sup> makes it unlawful for employers to fail or “refuse to hire, or to discharge, any employee, or otherwise discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of genetic information with respect to the employee; or to limit, segregate, or classify the employees of the 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.”<sup>3</sup> Further, GINA declares that “it shall be an unlawful employment practice for an employer to request, require, or purchase genetic information with respect to an employee or a family member of the employee.”<sup>4</sup> In addition, employment agencies, training programs, and labor organizations may not “cause or attempt to cause an employer to discriminate against an individual in violation of this chapter.”<sup>5</sup> Covered entities are also prohibited from retaliating against any individual for exercising his or her rights under GINA.<sup>6</sup>

The remedies and damages available under GINA are the same as allowed by Title VII, the Government Employee Rights Act of 1991, the Congressional Accountability Act, or Section 717 of the Civil Rights Act of 1964.<sup>7</sup> For most private employers, this means that an aggrieved employee might be entitled to injunctive relief, reinstatement or front pay, back pay, lost benefits, compensatory damages up to the statutory caps, and fees and costs, including attorney’s fees.<sup>8</sup>

### Fast Facts

Effective November 21, 2009, the Genetic Information Nondiscrimination Act of 2008 makes it unlawful for employers to:

- discriminate against employees because of genetic information;
- request genetic information about their employees or their employees’ families; or
- retaliate against employees for exercising their rights under the act.

GINA defines genetic information as “with respect to any individual, information about—(i) such individual’s genetic tests, (ii) the genetic tests of family members of such individual, and (iii) the manifestation of a disease or disorder in family members [(dependents and blood relations within four degrees)] of such individual.”<sup>9</sup> Genetic information also includes “any request for, or receipt of, genetic services, or participation in clinical research which includes genetic services, by such individual or any family member of such individual.”<sup>10</sup> It does not include “information about the sex or age of any individual.”<sup>11</sup>

### Statutory Exceptions and Limiting Provisions of GINA

GINA specifically recognizes certain exceptions. It is not an unlawful employment practice for an employer to acquire genetic information when health or genetic services are offered by the employer, including services offered as part of a wellness program.<sup>12</sup> GINA also permits employers to acquire genetic information if the employer uses it to monitor the biological effects of toxic substances in the workplace and if the employer provides written notice to the employees.<sup>13</sup> The monitoring must be required by and conducted in compliance with a state or federal law.<sup>14</sup> These two exceptions are available only under the following conditions: (1) the employee knowingly and voluntarily provides prior written consent, (2) only the employee (or family member receiving the services) and a licensed health care professional involved in providing the services receive individually identifiable information concerning the results, and (3) any individually identifiable genetic information is disclosed to the employer only in aggregate terms that do not disclose the identity of specific employees.<sup>15</sup>

Employers may also acquire genetic information (1) when the employer requests or requires family medical history from the employee to comply with the certification provisions of the Family and Medical Leave Act or similar state leave act, and (2) by purchasing documents that are commercially and publicly available that include family medical history (this exception includes newspapers, books, magazines, and periodicals, but specifically excludes medical databases and court records).<sup>16</sup>

Another exception provides employers with a defense. It is not an unlawful employment practice for a covered entity to “inadvertently request or require” the family medical history of the individual or family member of the individual.<sup>17</sup> The statute does not define what is meant by “inadvertently request or require.” It is important to note that this exception applies only to family medical history and not to genetic information more broadly.

All exceptions are allowed only to the extent that the information acquired is not used to violate the anti-discrimination and anti-retaliation provisions of GINA.<sup>18</sup> The statute also requires that employers maintain the confidentiality of any information obtained under the exceptions.<sup>19</sup>

GINA specifically excludes the potential for disparate impact claims—yet strangely leaves open legislative recognition of such claims at a later date.<sup>20</sup> On May 14, 2014, pursuant to the statute, a commission composed of eight individuals will review the developing science of genetics and make recommendations to Congress about whether disparate impact claims should be recognized.

### Historical Background and Congressional Justification of the Act

In 1990, a consortium of international geneticists from China, France, Germany, Japan, the United Kingdom, and the United States founded the \$3 billion Human Genome Project with the goal of determining the exact sequencing of the human genetic code, creating a public database to store and interpret the information, identifying the boundaries between genes and other features of raw DNA, and studying the legal, ethical, and social implications of their research. Four years later, Congress saw the introduction of the first genetic nondiscrimination legislation, followed the next year by no fewer than four additional pieces of legislation. That year, the Senate Committee on Health, Education, Labor, and Pensions (HELP) started studying the subject. In April 2007, HELP published its report, noting: “Only rarely is a scientific discovery so significant that it has the potential to transform both science and society. Humanity’s newly acquired ability to map and understand its own genetic traits may well be one such transforming discovery...The most immediate use of the data from sequencing the genome will be to increase our understanding of the links between genes and disease.”<sup>21</sup> The report acknowledged that medicine benefited by the discovery that mutations on the BRCA1 and BRCA2 genes were statistically linked to increased

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risks of breast and ovarian cancers. Tests to detect these mutations were of considerable benefit to women in evaluating their risks of disease and in taking steps to reduce those risks.<sup>22</sup>

The HELP report warned, however, that the committee received testimony on at least two occasions that many non-geneticists incorrectly regarded the presence of a genetic mutation as an unalterable prediction that a person will manifest the associated disorder.<sup>23</sup> “With these misconceptions so prevalent,” wrote the committee, “employers may come to rely on genetic testing to ‘weed out’ those employees who carry genes associated with that mutation.”<sup>24</sup> The committee concluded that fear of employers’ and insurance companies’ misuse of genetic information would lead many people to forego genetic testing that would improve their medical care.<sup>25</sup> In reaching this conclusion, the committee

pointed to several studies indicating a reluctance to submit to genetic testing. Specifically, the committee referred to a telephone survey in which 63 percent of the respondents said they would not take a genetic test if health insurers or employers could access the results.<sup>26</sup> Another survey indicated that 68 percent of patients reported they would not bill their insurance companies for genetic tests in clinical oncology for fear of discrimination.<sup>27</sup> Twenty-six percent stated they would take the tests only if they could use an alias.<sup>28</sup> Other studies revealed that only 43 percent of those at risk for hereditary colon cancer agreed to participate in genetic testing programs<sup>29</sup> and that 39 percent of those declining to participate cited fear of the effect on their health insurance coverage as the primary reason for declining.<sup>30</sup>

Despite what the committee described as “widespread” fears that genetic information would be misused, the committee was hard pressed to find actual examples of discrimination. The committee pointed to a 1989 survey by the United States Congress Office of Technology Assessment that reported that of 330 companies surveyed, 12 conducted genetic tests of employees.<sup>31</sup> The American Management Association conducted a more recent survey in 2000. Of the 2,133 employers surveyed, only seven reported that they conducted what they thought was genetic testing of their employees.<sup>32</sup> Notably absent from the committee’s report was any indication that the employers admitting to genetic testing had done so impermissibly.

Ultimately, the HELP report included only two examples of what the committee considered actual genetic discrimination. The committee reported that between 1968 and 1993, Lawrence Berkeley Laboratory performed pre-employment medical examinations that included blood and urine tests for syphilis, pregnancy, and sickle cell trait—without the employees’ knowledge or consent. Importantly, the laboratory was jointly operated by

state and federal agencies. When several employees sued the laboratory, the Ninth Circuit addressed the company’s failure to obtain consent, stating:

[I]t goes without saying that the most basic violation possible involves the performance of unauthorized tests—that is the non-consensual retrieval of previously unrevealed medical information that may be unknown even to plaintiff. These tests may also be viewed as searches in violation of fourth amendment rights that require fourth amendment scrutiny. The tests at issue in this case thus implicate rights protected under both the fourth amendment and the Due Process Clause of the fifth or fourteenth amendments.<sup>33</sup>


The second example cited by HELP also involved the non-consensual testing of employees. In 2001, Burlington Northern Santa Fe Railroad settled an EEOC charge alleging that it obtained genetic samples under false pretenses and used the samples to determine whether the employee’s symptoms, resembling carpal tunnel syndrome, were caused by a genetic mutation.<sup>34</sup>

Both houses of Congress passed GINA with only three dissenting votes between the two houses. Notably, then presidential candidates McCain, Obama, and Clinton each abstained.<sup>35</sup> Despite a dearth of evidence that genetic information discrimination was a widespread problem, the congressional findings provision of the statute notes, “Congress has collected substantial evidence that the American public and the medical community find the existing patchwork of State and Federal laws to be confusing and inadequate to protect them from discrimination.”<sup>36</sup>

## Existing Federal Protections Against Genetic Information Discrimination

Since February 10, 2000, federal employees have been protected under Executive Order 13145 against discharge or other restrictions in their employment or employment benefits on the basis of genetic information. Federal employers are also prohibited from the impermissible collection and unauthorized disclosure of employees’ genetic information.<sup>37</sup> The HELP report criticized Executive Order 13145, however, for lacking any specific enforcement provisions. To determine a violation of the executive order, the EEOC determines if the employee can establish a claim as an individual with a disability or as an individual regarded as having a disability under the Rehabilitation Act of 1973.<sup>38</sup>

The EEOC has extended similar protections to employees of private employers. The Americans with Disabilities Act covers not only individuals with a physical impairment, but also individuals regarded as having a substantially limiting impairment.<sup>39</sup> The EEOC compliance manual notes, “[t]his part of the definition of ‘disability’ applies to individuals who are subjected to discrimination on the basis of genetic information relating to illness, disease or other disorders. Covered entities that discriminate against individuals on the basis of such genetic information are regarding the individuals as having impairments that limit a major life activity.”<sup>40</sup> The manual provides an example of a person whose genetic profile reveals an increased susceptibility to colon cancer.



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Although the person is asymptomatic and may never develop colon cancer, his or her potential employer learns of the increased susceptibility and withdraws its conditional offer of employment because of concerns about productivity, insurance costs, and attendance. The compliance manual concludes that in this example, the person is covered by the "regarded as" part of the definition of disability.<sup>41</sup>

## Existing State Protections Against Genetic Information Discrimination

At the time Congress passed GINA, 34 states had already passed legislation prohibiting discrimination on the basis of genetic information.<sup>42</sup> Michigan amended the Persons With Disabilities Civil Rights Act (PWDCRA) in 2000 to specifically prohibit discrimination because of genetic information that is unrelated to the individual's ability to perform the duties of a particular job or position.<sup>43</sup> The amendment also prohibits employers from requiring that an individual submit to a genetic test or provide genetic information as a condition of employment or promotion and from acquiring, either directly or indirectly, genetic information concerning an employee, an applicant for employment, or a member of the employee's or applicant's family.<sup>44</sup>

The 2000 amendment to the PWDCRA was the result of the Governor's Commission on Genetic Privacy and Progress. The commission's 1999 report determined that "many people were concerned that genetic information could be used by employers to discriminate in hiring or promotion decisions."<sup>45</sup> Noticeably absent from the legislative analysis is any example of actual genetic discrimination. Tellingly, neither the House Fiscal Agency nor the Senate Fiscal Agency was able to estimate the fiscal impact of the amendment, because neither had data to estimate the number of potential genetic discrimination claims.<sup>46</sup> Eight years after the passage of the amendment, there have been no published opinions in which the plaintiff alleged a genetic discrimination claim under the PWDCRA.

## Conclusion

Despite the scientific advances in genetics and the resulting proliferation of genetic information nondiscrimination protections on both the state and federal levels, there is not any notable evidence of widespread misuse of genetic information by employers. GINA does not, on its face, restrict any common practice among employers, nor does it provide substantially stronger protections than already afforded by Michigan's PWDCRA. Practitioners should be aware, however, that GINA does provide more specific prohibitions and defenses than the PWDCRA. ■



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8. 42 USCA 1981a and 2000e-5(g).

9. 42 USCA 2000ff(4).

10. *Id.*

11. *Id.*

12. 42 USCA 2000ff-1(b)(2).

13. 42 USCA 2000ff-1(b)(5).

14. *Id.*

15. 42 USCA 2000ff-1(b)(2) and 2000ff-1(b)(5).

16. 42 USCA 2000ff-1(b)(3) and 2000ff-1(b)(4).

17. 42 USCA 2000ff-1(b)(1).

18. 42 USCA 2000ff-1(c).

19. 42 USCA 2000ff-5.

20. 42 USCA 2000ff-7.

21. S. Rep. No. 110-48, at 5 (2007).

22. *Id.*

23. *Id.* at 6.

24. *Id.*

25. *Id.*

26. *Id.*

27. *Id.*

28. *Id.*

29. *Id.*

30. *Id.*

31. *Id.* at 8.

32. *Id.*

33. *Norman-Bloodsaw v Lawrence Berkeley Laboratory*, 135 F3d 1260, 1269 (CA 9, 1998).

34. S. Rep. No. 110-48, at 10.

35. S. Vote No. 110-113 (April 24, 2008) and H. Roll Call No. 110-261 (April 25, 2007).

36. PL 110-233, § 2(5), 122 Stat 881.

37. Executive Order 13145.

38. EEOC Notice No. 915.002, *EEOC Policy Guidance on Executive Order 13145* (July 26, 2000), available at <<http://www.eeoc.gov/policy/docs/guidance-genetic.html>> (accessed December 15, 2008).

39. 42 USCA 12102(2)(c).

40. EEOC Compliance Manual § 902.8(a).

41. EEOC Compliance Manual § 902.8(a).

42. S. Rep. No. 110-48, at 13.

43. MCLA 37:1202(a).

44. MCLA 37:1202(h).

45. Michigan House Fiscal Agency Bill Analysis, SB 593, February 22, 2000.

46. Michigan House Fiscal Agency Bill Analysis, SB 593, February 22, 2000 and Michigan Senate Fiscal Agency Bill Analysis, SB 815, October 26, 1999.

## FOOTNOTES

1. 42 USCA 2000ff *et seq.*

2. 42 USCA 2000e *et seq.*

3. 42 USCA 2000ff-1(a).

4. 42 USCA 2000ff-1(b).

5. 42 USCA 2000ff-2(a), 2000ff-3(a), and 2000ff-4(a).

6. 442 USCA 2000ff-6(f).

7. 42 USCA 2000ff-6(a) through 2000ff-6(e).