

The Genetic Information Non-Discrimination Act

By Joseph J. Lazzarotti and Julia Ebert

Introduction

For a number of years, Congress had attempted to craft legislation to address the increasing likelihood for abuses relating to the use and disclosure of “genetic information” stemming from the recent advancements in genetics and the fact that genetic information has become more readily available. Congress recognized that the existing patchwork of State and Federal laws intending to protect the public from genetic discrimination was confusing and inadequate.¹ To address these concerns, Congress sought to establish a national and uniform basic standard to fully protect the public from discrimination and allay their concerns about the potential for discrimination, enabling them to more freely take advantage of genetic testing, technologies, research, and new therapies.

The Genetic Information Nondiscrimination Act of 2008 (“GINA” or “the Act”)² is the culmination of these efforts. Passed almost unanimously by Congress and signed into law on May 21, 2008, by President Bush, GINA in essence prohibits discrimination on the basis of genetic information in the areas of employment and health insurance by restricting the use of, access to and disclosure of genetic information. The Act applies to group and individual health insurers, group health plans, public and private sector employers, employment agencies, and labor organizations.

After a brief discussion of efforts by states to curb genetic discrimination, this article highlights some of the key provisions of GINA affecting group health plans and employers, including employer sponsored wellness programs.

Genetic Discrimination

State Laws

“States first addressed the use of genetic information in the workplace in the 1970s and 1980s by outlawing

discrimination against job applicants with the sickle cell trait.”³ Since then, states have created various statutory frameworks and imposed a range of regulation on employers with regard to genetic testing and the use of genetic information. For example, thirty-four states and the District of Columbia have prohibited genetic discrimination in hiring, firing, and terms, conditions, and privileges of employment.⁴ Twenty states have prohibited

³ Sara Abiola, *The Genetic Information Non Discrimination Act of 2008: “First Major Civil Rights Bill of the Century” Bars Misuse of Genetic Test Results*, 36 J.L. MED. & ETHICS 856, 856 (Winter 2008) (citing National Conference of State Legislatures, “State Genetics Employment Laws,” available at <http://www.ncsl.org/programs/health/genetics/ndscrim.htm> (last visited October 16, 2008)); see also Kevin M. Maroney, *Prohibiting Genetic Discrimination* 81 Wis. Law 12, 14 (Nov. 2008) (citing FL Stat. § 48.075 (1978); La. Stat. § 23:1001 (1982); N.J. Stat. § 10:5-12 (1981); N.Y. Stat § 48-a (1990).

⁴ ARIZ. REV. STAT. §§ 41-1463, *et seq.*, ARK. CODE ANN. §§ 11-5-401, *et seq.*; CAL. GOV’T. §§ 12926, 12940; CONN. GEN. STAT. ANN. § 46a-60; DEL. CODE ANN. Tit. 19 §§ 710, 711; D.C. CODE ANN. §§ 2-1401.01, *et seq.*; HAW. REV. STAT. §§ 378-1, *et seq.*; IDAHO CODE §§ 39-8302, *et seq.*; 410 ILL. COMP. STAT. § 513/25; IOWA ACTS § 729.6; KAN. STAT. ANN. § 44-1001, *et seq.*; LA. REV. STAT. ANN. §§ 22:302, *et seq.*, 23:368, *et seq.*; ME. REV. STAT. ANN. Tit. 5 § 19302; MD. CODE ANN. INS. §§ 49B-15, *et seq.* (repealed 2009, MD Legis § 120 (H.B. 51)); MASS. GEN. LAWS ANN. 151B § 1, *et seq.*; MICH. COMP. LAWS ANN. §§ 37.1201, *et seq.*, MINN. STAT. ANN. § 181.974; MO. STAT. ANN. §§ 375.1300, *et seq.*; NEB. REV. STAT. ANN. § 48-236; NEV. REV. STAT. ANN. § 613.345; N.H. REV. STAT. ANN. §§ 141-H:1, *et seq.*; N.J. STAT. ANN. §§ 10:5-5, *et seq.*; N.M. STAT. ANN. § 24-21-1, *et seq.*; N.Y. EXEC. LAW §§ 292, 296. (amended by N.Y. LEGIS § 56); N.C. GEN. STAT. §§ 95-28.1A, *et seq.*, 58-68-30, *et seq.*; OKLA. STAT. ANN. Tit. 36 §§ 3614.1, *et seq.*; OR. REV. STAT. §§ 659A.300, *et seq.*; R.I. GEN. LAWS §§ 28-6.7-1, *et seq.*; S.D. CODIFIED LAWS §§ 60-2-20; TEX LABOR CODE ANN. §§ 21.401, *et seq.*; UTAH CODE ANN. §§ 26-45-101, *et seq.*; VT. STAT. ANN. §§ 18:9331, *et seq.*; VA. CODE ANN. §§ 40.1-28.7:1, *et seq.*; WASH REV. CODE § 49.44.180; WIS. STAT. ANN. §§ 111.372, *et seq.*

¹ See Genetic Information Nondiscrimination Act, 493 H.R. 493, 110th Cong. § 2, para. 5 (2008) (enacted).

² Genetic Information Nondiscrimination Act, Pub. L. No. 110-233 (2008).

employers from requesting genetic information or testing.⁵ Twenty-five states have prohibited employers from requiring genetic information or testing.⁶ Sixteen states have prohibited employers from performing genetic testing.⁷ Eleven states have prohibited employers from obtaining genetic information or test results.⁸

⁵ ARK. CODE ANN. §§ 11-5-401, *et seq.*; CONN. GEN. STAT. ANN. § 46a-60; IDAHO CODE §§ 39-8302, *et seq.*; IOWA ACTS § 729; KAN. STAT. ANN. § 44-1001, *et seq.*; LA. REV. STAT. ANN. §§ 22:302, *et seq.*, 23:368, *et seq.*; ME. REV. STAT. ANN. Tit. 5 § 19302; MD. CODE ANN. INS. §§ 49B-15, *et seq.* (repealed 2009, MD LEGIS § 120 (H.B. 51)); MASS. GEN. LAWS ANN. 151B § 1, *et seq.*; MINN. STAT. ANN. § 181.974; NEV. REV. STAT. ANN. § 613.345; N.H. REV. STAT. ANN. §§ 141-H:1, *et seq.*; N.Y. EXEC. LAW §§ 292, 296. (amended by N.Y. LEGIS § 56); OKLA. STAT. ANN. Tit. 36 §§ 3614.1, *et seq.*; OR. REV. STAT. §§ 659A.300, *et seq.*; R.I. GEN. LAWS §§ 28-6.7-1, *et seq.*; S.D. CODIFIED LAWS §§ 60-2-20; UTAH CODE ANN. §§ 26-45-101, *et seq.*; VA. CODE ANN. §§ 40.1-28.7:1, *et seq.*; WIS. STAT. ANN. §§ 111.372, *et seq.*

⁶ ARK. CODE ANN. §§ 11-5-401, *et seq.*; CONN. GEN. STAT. ANN. § 46a-60; HAW. REV. STAT. §§ 378-1, *et seq.*; IDAHO CODE §§ 39-8302, *et seq.*; IOWA ACTS § 729.6; KAN. STAT. ANN. § 44-1001, *et seq.*; LA. REV. STAT. ANN. §§ 22:302, *et seq.*, 23:368, *et seq.*; MD. CODE ANN. INS. §§ 49B-15, *et seq.* (repealed 2009, MD LEGIS § 120 (H.B. 51)); MASS. GEN. LAWS ANN. 151B § 1, *et seq.*; MICH. COMP. LAWS ANN. §§ 37.1201, *et seq.*; MINN. STAT. ANN. § 181.974; NEB. REV. STAT. ANN. § 48-236; NEV. REV. STAT. ANN. § 613.345; N.H. REV. STAT. ANN. §§ 141-H:1, *et seq.*; N.Y. EXEC. LAW §§ 292, 296. (amended by N.Y. LEGIS § 56); OKLA. STAT. ANN. Tit. 36 §§ 3614.1, *et seq.*; OR. REV. STAT. §§ 659A.300, *et seq.*; R.I. GEN. LAWS §§ 28-6.7-1, *et seq.*; S.D. CODIFIED LAWS §§ 60-2-20; TEX LABOR CODE ANN. §§ 21.401, *et seq.*; UTAH CODE ANN. §§ 26-45-101, *et seq.*; VT. STAT. ANN. §§ 18:9331, *et seq.*; VA. CODE ANN. §§ 40.1-28.7:1, *et seq.*; WASH. REV. CODE § 49.44.180; WIS. STAT. ANN. §§ 111.372, *et seq.*

⁷ CAL. GOV'T. §§ 12926, 12940; IOWA ACTS § 729.6; LA. REV. STAT. ANN. §§ 22:302, *et seq.*, 23:368, *et seq.*; MASS. GEN. LAWS ANN. 151B § 1, *et seq.*; MICH. COMP. LAWS ANN. §§ 37.1201, *et seq.*; MINN. STAT. ANN. § 181.974; NEV. REV. STAT. ANN. § 613.345; N.H. REV. STAT. ANN. §§ 141-H:1, *et seq.*; N.Y. EXEC. LAW §§ 292, 296. (amended by N.Y. LEGIS § 56); OKLA. STAT. ANN. Tit. 36 §§ 3614.1, *et seq.*; OR. REV. STAT. §§ 659A.300, *et seq.*; R.I. GEN. LAWS §§ 28-6.7-1, *et seq.*; S.D. CODIFIED LAWS §§ 60-2-20; VT. STAT. ANN. §§ 18:9331, *et seq.*; VA. CODE ANN. §§ 40.1-28.7:1, *et seq.*; WIS. STAT. ANN. §§ 111.372, *et seq.*

⁸ ARK. CODE ANN. §§ 11-5-401, *et seq.*; IDAHO CODE §§ 39-8302, *et seq.*; KAN. STAT. ANN. § 44-1001, *et seq.*; MASS. GEN. LAWS ANN. 151B § 1, *et seq.*; MICH. COMP. LAWS ANN. §§ 37.1201, *et seq.*; MINN. STAT. ANN.

States also have imposed varied and sometimes conflicting duties on insurers. For example, some state laws have prohibited only group insurance plans from genetic discrimination.⁹ Most, however, have prohibited both individual and group policies from genetic discrimination.¹⁰ Hawaii, Nebraska, and West Virginia, on the other hand,

§ 181.974; N.Y. EXEC. LAW §§ 292, 296. (amended by N.Y. LEGIS § 56); OKLA. STAT. ANN. Tit. 36 §§ 3614.1, *et seq.*; OR. REV. STAT. §§ 659A.300, *et seq.*; S.D. CODIFIED LAWS §§ 60-2-20; UTAH CODE ANN. §§ 26-45-101, *et seq.*

⁹ ALASKA STAT. §§ 21.54.100, *et seq.*; IOWA ACTS § 513b.9a, 10(4)(a)(1); N.D. LAWS §§ 26.1-36-01, *et seq.*; S.D. CODIFIED LAWS §§ 58-18-45, 58-18B-27; WYO. STAT. ANN. §§ 26-19-107, 26-19, 306, 26-22-502, *et seq.*

¹⁰ ALA. CODE §§ 27-53-1, *et seq.*; ARIZ. REV. STAT. §§ 20-448, 448.02; ARK. CODE ANN. §§ 23-86-30, *et seq.*, 23-66-320; CAL. INS. §§ 742.405, *et seq.* § 10140; COLO. REV. STAT. § 10-3-1104.7; CONN. GEN. STAT. ANN. § 38a-816, 476; DEL. CODE ANN. Tit. 16 § 1220, 18 § 2317; D.C. CODE ANN. §§ 2-1401.01, *et seq.*; FL. STAT. ANN. §§ 627.4301, 627.6419, 636.0201, 641.31071, 641.31073, 641.438; GA. CODE ANN. §§ 33-54-1, *et seq.*; IDAHO CODE §§ 41-2221, 41-3940, 41-4708; 215 ILL. COMP. STAT. §§ 97/20, 97/25, 410 ILL. COMP. STAT. §§ 513/10, *et seq.*; IND. CODE ANN. §§ 27-4-1-4, *et seq.* 8-26-1, *et seq.*; KAN. STAT. ANN. § 40-2259; KY. REV. STAT. ANN. §§ 304.12-085, 304.17a-200, *et seq.*; LA. REV. STAT. ANN. §§ 22:1022, *et seq.*, 22:1061, *et seq.*, 22:1964; ME. REV. STAT. ANN. Tit. 24-A §§ 2159, 2204, 2850, 22 § 1711; MD. CODE ANN. INS. §§ 27-208, 27-909; MASS. GEN. LAWS ANN. 111 § 70G, 175 § 108H, 175 § 108I, 175 § 120E; 176B § 5B, 176G § 24, 176 I § 4A, MICH. COMP. LAWS ANN. §§ 550-1401, *et seq.*, MINN. STAT. ANN. § 72A.139; MO. STAT. ANN. §§ 375.1300, *et seq.*; MONT. CODE ANN. § 33-18-206, §§ 33-18-901, *et seq.*; NEV. REV. STAT. ANN. §§ 689A.417, 689A.585, 689b.069, 689b.420, *et seq.*, 689c.076, *et seq.*, 689c.193, *et seq.*; 695B.317, *et seq.*; N.H. REV. STAT. ANN. §§ 141-H:1, *et seq.*; N.J. STAT. ANN. §§ 10:5-5, *et seq.*, 17:48-6.18, 17:48A-6.11, 17:48E-15.2, 17B:26-3.2, *et seq.*, 17B:27A-2, *et seq.*, 17B-30-12; N.M. STAT. ANN. § 24-21-1, *et seq.*; N.Y. INS. LAW §§ 2401, 2612, 2615, 3232, 4305, *et seq.*, N.C. GEN. STAT. §§ 58-3-25, *et seq.* 58-68-30, *et seq.*, OHIO REV. CODE ANN. §§ 1751.65, 3901.01, *et seq.*, § 3924.01, *et seq.*; OKLA. STAT. ANN. Tit. 36 §§ 3614.1, *et seq.* 4502; OR. REV. STAT. §§ 743.730, 746.135, 746.632; R.I. GEN. LAWS §§ 27-18-52, *et seq.*, 27-19-44, *et seq.*, 27-20-39, *et seq.*, 27-41-53, *et seq.*, 27-50-3, *et seq.*; S.C. CODE ANN. §§ 38-93-10, *et seq.*, 56-7-2701, *et seq.* § 56-7-2802, *et seq.*, 56-51-116; TEX. INS. CODE ANN. §§ 546.001, *et seq.*, 846.203, 1501.103; UTAH CODE ANN. §§ 26-45-101, *et seq.*, VT. STAT. ANN. §§ 8:4724, 18:9331, *et seq.*, VA. CODE ANN. §§ 38.2-508.4, 38.2-613, 38.2-3431, 38.2-3551, 38.2-5001, *et seq.*; WIS. STAT. ANN. §§ 631.89, *et seq.*, 632.746, *et seq.*

have prohibited only individual health plans from genetic discrimination.¹¹ Mississippi, Pennsylvania, and Washington have not legislated genetic discrimination by insurers. Forty-four states and the District of Columbia have prohibited insurers from basing eligibility or premiums on genetic discrimination.¹² Twenty-six states and the District of Columbia have prohibited insurers from

requiring genetic testing of applicants.¹³ Forty-two states and the District of Columbia have prohibited insurers from using genetic information for risk assessment or classification.¹⁴ Twenty-six states have prohibited insurers from disclosing genetic information without the insured's

¹¹ HAW. REV. STAT. §§ 431:10A-118, 404.5, 432:1-607, 404.5, 432d-26; NEB. REV. STAT. ANN. §§ 44-787, *et seq.*, §§ 44-5402.02, *et seq.*, §§ 44-6910, *et seq.*; W. VA. CODE ANN. §§ 33-15-2a, 33-16-1a, *et seq.*

¹² ALA. CODE §§ 27-53-1, *et seq.*; ALASKA STAT. §§ 21.54.100, *et seq.*; ARIZ. REV. STAT. §§ 20-448, 448.02; ARK. CODE ANN. §§ 23-86-30, *et seq.*, § 23-66-320; CAL. INS. §§ 742.405, *et seq.* § 10140; COLO. REV. STAT. § 10-3-1104.7; CONN. GEN. STAT. ANN. § 38a-816, 476; DEL. CODE ANN. Tit. 16 § 1220, 18 § 2317; D.C. CODE ANN. §§ 2-1401.01, *et seq.*; FL. STAT. ANN. §§ 627.4301, 627.6419, 636.0201, 641.31071, 641.31073, 641.438; GA. CODE ANN. §§ 33-54-1, *et seq.*; HAW. REV. STAT. §§ 431:10A-118, 404.5, 432:1-607, 404.5, 432d-26; IDAHO CODE §§ 41-2221, 41-3940, 41-4708; 215; ILL. COMP. STAT. §§ 97/20, 97/25, 410 ILL. COMP. STAT. §§ 513/10, *et seq.*; IND. CODE ANN. §§ 27-4-1-4, *et seq.* 8-26-1, *et seq.*; IOWA ACTS § 513b.9a, 10(4)(a)(1); KAN. STAT. ANN. § 40-2259; KY. REV. STAT. ANN. §§ 304.12-085, 304.17a-200, *et seq.*; LA. REV. STAT. ANN. §§ 22:1022, *et seq.*, 22:1061, *et seq.*, 22:1964; ME. REV. STAT. ANN. Tit. 24-A §§ 2159, 2204, 2850, 22 § 1711; MD. CODE ANN. INS. §§ 27-208, 27-909; MASS. GEN. LAWS ANN. 111 § 70G, 175 § 108H, 175 § 108I, 175 § 120E; 176B § 5B, 176G § 24, 176 I § 4A; MINN. STAT. ANN. § 72A.139; MO. STAT. ANN. §§ 375.1300, *et seq.*; MONT. CODE ANN. § 33-18-206, §§ 33-18-901, *et seq.*; NEV. REV. STAT. ANN. §§ 689A.417, 689A.585, 689b.069, 689d.420, *et seq.*, 689c.076, *et seq.*, 689c.193, *et seq.*, 689b.317, *et seq.*; N.H. REV. STAT. ANN. §§ 141-H:1, *et seq.*; N.J. STAT. ANN. §§ 10:5-5, *et seq.*, 17:48-6.18, 17:48A-6.11, 17:48E-15.2, 17B:26-3.2, *et seq.*, 17B:27A-3, *et seq.*, 17B:30-12; N.M. STAT. ANN. § 24-21-1, *et seq.*; N.Y. INS. LAW §§ 2401, 2612, 2615, 3232, 4305, *et seq.*; N.C. GEN. STAT. §§ 58-3-25, *et seq.* 58-68-30, *et seq.*; OHIO REV. CODE ANN. §§ 1751.65, 3901.01, *et seq.*, 3924.01, *et seq.*; OKLA. STAT. ANN. Tit. 36 §§ 3614.1, *et seq.* 4502; OR. REV. STAT. §§ 743.730, 746.135, 746.632; R.I. GEN. LAWS §§ 27-18-52, *et seq.*, 27-19-44, *et seq.*, 27-20-39, *et seq.*, 27-41-53, *et seq.*, 27-50-3, *et seq.*; S.C. CODE ANN. §§ 38-10-10, *et seq.*; S.D. CODIFIED LAWS §§ 58-18-45, 58-18B-27; TENN. CODE ANN. §§ 56-7-2701, *et seq.* 56-7-2802, *et seq.*, 56-51-116.; TEX. INS. CODE ANN. §§ 546.001, *et seq.*, 546.203, 1501.103; UTAH CODE ANN. §§ 26-45-101, *et seq.*; VT. STAT. ANN. §§ 8:4724, 18:9331, *et seq.*; VA. CODE ANN. §§ 38.2-508.4, 38.2-613, 38.2-3431, 38.2-3551, 38.2-5001, *et seq.*; W. VA. CODE ANN. §§ 33-15-2a, 33-16-1a, *et seq.*;

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