RECENT LEGISLATION

HEALTH LAW — GENETICS — CONGRESS RESTRICTS USE OF GENETIC INFORMATION BY INSURERS AND EMPLOYERS. — Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (to be codified in scattered sections of 26, 29, and 42 U.S.C.).

Fear of genetic discrimination has risen with the availability of genetic testing — many Americans worry that tests indicating tendencies toward disease will prevent them from obtaining insurance and jobs.¹ Although these concerns may be unfounded,2 even baseless fear could pose a public health threat: fear may deter people from getting valuable genetic tests, seeking treatments that would reveal genetic conditions to others, or participating in genetic research.³ In response, most states passed laws restricting use of genetic information by health insurers and employers,⁴ Congress banned use of such information to determine eligibility for or certain exclusions from group health plans,⁵ and President Clinton issued an executive order prohibiting genetic discrimination in federal employment.⁶ Recently, President George W. Bush signed into law the Genetic Information Nondiscrimination Act of 2008⁷ (GINA), outlawing genetic discrimination in health insurance and employment. The Act provides reasonable protection from employer discrimination, but its blinkered focus on genetics creates a false solution for health insurance. Genetic conditions need not be privi-

¹ See, e.g., ALLEN BUCHANAN ET AL., FROM CHANCE TO CHOICE: GENETICS & JUS-TICE 61 (2000); Amy Harmon, Fear of Insurance Trouble Leads Many To Shun or Hide DNA Tests, N.Y. TIMES, Feb. 24, 2008, § 1, at 1; National Human Genome Research Institute, Genetic Discrimination, http://www.genome.gov/10002077 (last visited Dec. 6, 2008).

² See, e.g., Gaia Bernstein, The Paradoxes of Technological Diffusion: Genetic Discrimination and Internet Privacy, 39 CONN. L. REV. 241, 258 (2006) (noting that survey research "overwhelmingly demonstrates that genetic discrimination by employers and insurers is rare and is generally on the decline"). But see Paul Steven Miller, Is There a Pink Slip in My Genes?: Genetic Discrimination in the Workplace, 3 J. HEALTH CARE L. & POL'Y 225, 234 (2000) (claiming that "fears of genetic discrimination are not baseless" because some discrimination has been reported).

³ See, e.g., Bernstein, supra note 2, at 261-62; Henry T. Greely, Banning Genetic Discrimination, 353 NEW ENG. J. MED. 865, 867 (2005); Harmon, supra note 1.

⁴ See Robert B. Lanman, An Analysis of the Adequacy of Current Law in PROTECTING AGAINST GENETIC DISCRIMINATION IN HEALTH INSURANCE AND EM-PLOYMENT 10-11 (2005) (noting that, by 2004, forty-seven states and the District of Columbia had such laws for health insurance and thirty-two states had them for employment).

⁵ See id. at 2 (describing the Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (codified in scattered sections of 26, 29, and 42 U.S.C.)).

⁶ Exec. Order No. 13,145, 3 C.F.R. 235 (2001), reprinted in 42 U.S.C. § 2000e-16 (Supp. V

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⁷ Pub. L. No. 110-233, 122 Stat. 881 (to be codified in scattered sections of 26, 29, and 42 U.S.C.).

leged over many nongenetic ones, and furthermore, GINA may do little to stop discrimination, increase inequality, stymie broader legislation, and impair the insurance system.

Genetic discrimination in America traces back to the eugenics movement of the early twentieth century, when arguments based on genetics supported restrictive immigration laws — "Nordics deteriorate when mixed with other races" - and sterilization laws - "[t]hree generations of imbeciles are enough."9 But then Nazi eugenics turned public opinion against not only genetic discrimination but also genetic science.¹⁰ As the science has revived,¹¹ concern over genetic discrimination has reemerged — due, in part, to several cases of involuntary testing. The discovery of a gene for sickle cell anemia led to mandatory testing of African Americans and denial of jobs and insurance in the 1970s. 12 In Norman-Bloodsaw v. Lawrence Berkeley Laboratory, 13 employees alleged that pre-employment medical examinations secretly tested for sickle cell anemia, syphilis, and pregnancy.¹⁴ In 2002, the Equal Employment Opportunity Commission settled a suit that also concerned secret genetic testing of employees, this time by the Burlington Northern Santa Fe Railway Company. 15

In 1995, Representative Louise Slaughter introduced federal genetic nondiscrimination legislation,¹⁶ and such legislation has appeared in each subsequent Congress.¹⁷ When she reintroduced GINA in 2007, the bill garnered widespread support, including 224 cosponsors.¹⁸ It passed through the Committees on Education and Labor, Ways and Means, and Energy and Commerce and then passed the House, 420 to

 $^{^8}$ Daniel J. Kevles, In the Name of Eugenics 97 (2d ed. 1995) (quoting then–Vice President Calvin Coolidge) (internal quotation mark omitted).

⁹ Id. at 111 (quoting Buck v. Bell, 274 U.S. 200, 207 (1927) (Holmes, J.)).

¹⁰ See id. at 210.

¹¹ See Rebecca Porter, New Law Will Protect Employees and Insureds from Genetic Bias, TRIAL, July 2008, at 70, 72 (noting growth of genetics after the 2003 decoding of human DNA).

¹² See Melinda B. Kaufmann, Genetic Discrimination in the Workplace: An Overview of Existing Protections, 30 LOY. U. CHI. L.J. 393, 402–03 (1999); Lisa Stein, Congress Passes Bill Barring Genetic Discrimination, SCI. AM., May 1, 2008, http://www.sciam.com/article.cfm?id=bill-bars-genetic-discrimination.

^{13 135} F.3d 1260 (9th Cir. 1998).

¹⁴ Id. at 1264–66. Lawrence Berkeley Laboratory conditioned its offers of employment on medical examinations, and employees alleged that the tests occurred without their knowledge or consent and without privacy safeguards for the test results; employees sued for violations of Title VII of the Civil Rights Act of 1964, the Americans with Disabilities Act (ADA), and the federal and California constitutional rights to privacy. Id.

¹⁵ See Porter, supra note 11, at 72.

¹⁶ Protecting Workers from Genetic Discrimination: Hearing on H.R. 493 Before the Subcomm. on Health, Employment, Labor and Pensions of the H. Comm. on Education and Labor, 110th Cong. 7 (2007) (statement of Rep. Louise M. Slaughter).

¹⁷ See National Human Genome Research Institute, supra note I (providing a "Genetic Non-discrimination Federal Legislation Archive" with legislation from each Congress).

^{18 154} CONG. REC. H2958 (daily ed. May 1, 2008) (statement of Rep. Sessions).

3.19 After a minor amendment,20 the bill passed the Senate unanimously21 and returned to the House, passing 414 to 1.22

GINA defines genetic information as information about "(i) [an] 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 of such individual,"²³ but not sex or age.²⁴ A genetic test is "an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes,"²⁵ but, in the context of health insurance, the Act provides an exception for "an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition."²⁶ This exception bars discrimination claims stemming from an insurer's consideration of tests related to detectable existing phenotypical conditions.

Title I provides for genetic nondiscrimination in health insurance. It prohibits group health plans from adjusting premiums or contributions on the basis of genetic information;²⁷ from requiring genetic tests or, except for certain research purposes, even requesting them;²⁸ and from requesting, requiring, or purchasing genetic information for underwriting or enrollment purposes.²⁹ Violations of these provisions all incur penalties.³⁰ GINA imposes parallel restrictions on insurers in the individual market and also prohibits such insurers from using genetic information to determine eligibility.³¹ Medicare policy issuers fall under the same restrictions on obtaining genetic tests and genetic information and cannot use genetic information to determine the issuance, effectiveness, or price of a policy.³² Finally, Title I requires treatment of genetic information as health information for privacy purposes un-

¹⁹ 153 CONG. REC. H4108 (daily ed. Apr. 25, 2007) (roll number 261).

²⁰ Compare Genetic Information Nondiscrimination Act of 2007, H.R. 493, 110th Cong. (as received and read the first time by Senate, Apr. 26, 2007), with 154 CONG. REC. S3311-22 (daily ed. Apr. 23, 2008) (Senate Amendment 4573).

²¹ 154 CONG. REC. S3374 (daily ed. Apr. 24, 2008) (roll number 113).

 $^{^{22}\,}$ 154 CONG. REC. H2979–80 (daily ed. May 1, 2008) (roll number 234). Congressman Ron Paul cast the lone opposing vote. Id.

²³ GINA § 101(d), 122 Stat. at 885. This definition remains the same throughout the Act.

²⁴ Id

²⁵ Id. This definition also remains the same throughout the Act.

 $^{^{26}}$ Id. $\$ 101(d), 122 Stat. at 886. Compare id. (including exception in case of health insurance), with id. $\$ 201(6), 122 Stat. at 907 (omitting exception in case of employment).

²⁷ Id. §§ 101(a), 102(a)(1), 103(a), 122 Stat. at 883, 888, 896.

²⁸ *Id.* §§ 101(b), 102(a)(2), 103(b), 122 Stat. at 883–84, 888–89, 896–97. Insurers may request testing only for research purposes and only if 1) the request is written and comes with clear indication of its voluntariness and lack of effect on insurance coverage and premiums, and 2) the Secretary of Health and Human Services has been notified in writing of the research activities. *Id.*

²⁹ Id. §§ 101(b), 102(a)(2), 103(b), 122 Stat. at 884, 889, 897.

 $^{^{30}}$ Id. §§ 101(e), 102(a)(5), 103(e), 122 Stat. at 886–88, 891–92, 899.

³¹ Id. § 102(b), 122 Stat. at 892-95.

³² Id. § 104, 122 Stat. at 899–903.

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der the Health Insurance Portability and Accountability Act of 1996³³ and prohibits use or disclosure of genetic information for underwriting purposes.³⁴

Title II outlaws genetic discrimination by employers, employment agencies, labor organizations, and joint labor-management committees. In addition to proscribing traditional discriminatory practices, such as biased hiring and firing decisions, different compensation, different treatment, and exclusion from groups,³⁵ GINA prohibits these organizations from adversely limiting, segregating, or classifying employees on the basis of genetic information;³⁶ from requesting, requiring, or purchasing such information except under certain conditions;³⁷ from keeping employees' genetic information other than as confidential medical records in separate files;³⁸ and from disclosing employees' genetic information except under certain conditions.³⁹ GINA does not permit disparate impact on the basis of genetic information as a cause of action, but it does provide for the establishment of a commission in 2014 to consider whether such a cause of action should be created.⁴⁰

Although superficially appealing, GINA suffers from significant flaws. It implies and promotes genetic exceptionalism — the idea that genetic information needs special treatment⁴¹ — despite lacking a sound basis for separating genetic conditions from nongenetic ones that people did not knowingly cause and cannot change.⁴² Without such a basis, GINA needs a positive cost-benefit analysis to justify itself. Many might think that legislation providing any additional discrimination protection must be beneficial, but Title I fails to create a net benefit in health insurance — although Title II succeeds in employment. Title I solves few problems and may increase inequality,

³³ Pub. L. No. 104-191, 110 Stat. 1936 (codified in scattered sections of 26, 29, and 42 U.S.C.).

³⁴ GINA § 105, 122 Stat. at 903–05.

 $^{^{35}}$ Id. §§ 202–205, 122 Stat. at 907–13.

³⁶ *Id*.

³⁷ GINA provides exceptions for information obtained inadvertently, used for employer health services and disclosed only to health personnel, needed to comply with family and medical leave laws, obtained in a commercial and public form, used appropriately for genetic monitoring of effects of toxins in the workplace, or acquired by an employer that is a DNA analyzer for law enforcement and uses the information for quality control. *Id.*

³⁸ Id. § 206, 122 Stat. at 913-14.

 $^{^{39}}$ GINA provides exceptions for provision of information upon written request of the employee, for the purpose of approved research, in response to certain court orders, for government investigations of compliance with GINA, in connection with family and medical leave laws, and in certain cases of public health threats. *Id.*

⁴⁰ Id. § 208, 122 Stat. at 917-18.

⁴¹ See, e.g., Deborah Hellman, What Makes Genetic Discrimination Exceptional?, 29 AM. J.L. & MED. 77, 83 & n.28 (2003); Mark A. Rothstein, Genetic Exceptionalism and Legislative Pragmatism, 35 J.L. MED. & ETHICS (SPECIAL SUPPLEMENT) 59, 59 (2007).

⁴² See, e.g., Rothstein, supra note 41, at 59 ("Most commentators have cautioned against genetic exceptionalism [It] represents poor public policy."); id. at 61–62.

impede the provision of healthcare coverage that supporters stated as their goal,⁴³ and weaken the insurance system.

Though instinctively accepted by most people outside the bioethics community,⁴⁴ genetic exceptionalism produces unsettling results. Consider three women who have the same increased probability of breast cancer: one who carries the BRCA1 gene, a second who has unknown environmental hazards in her neighborhood,45 and a third who was exposed to diethylstilbestrol as a fetus.46 None of these women deserves blame for her predisposition to cancer, but under GINA an insurer could deny coverage or raise premiums based on the exposurebased conditions but not the genetic one. Discomfort with this result probably stems from the intuition that well-being should depend not on pure luck but rather on what we think of as conscious choices.⁴⁷ The blamelessness of all three women makes it difficult to support giving benefits to the first woman but denying them to the others. The apparent equivalence of this genetic and nongenetic information makes separate genetic antidiscrimination legislation questionable why should we care less about those with nongenetic health risks?

Under a more concrete analysis of the effects of GINA, Title I still fails, as its costs outweigh its benefits. The potential benefits — expanded access to healthcare and reduced fear of discrimination — certainly have merit, but GINA likely will have minimal effect on them. No evidence exists of insurers secretly or forcibly using genetic testing, and very little exists of their using genetic information in a discriminatory manner.⁴⁸ Given current levels of discrimination, GINA will have a minute immediate effect. It strikes a preemptive blow against future

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⁴³ See 154 CONG. REC. H2978 (daily ed. May 1, 2008) (statement of Rep. Stupak) ("[T]hese provisions will ensure that genetic material... is not used to limit families' access to health care."); id. at H2976 (statement of Rep. Engel) ("[GINA] will make a true impact on the health care of our Nation."); id. at H2974 (statement of Rep. Schwartz) ("Today, Americans buy health coverage... expecting that they have secured access for needed health services.... [GINA] is important for all Americans and their access to health coverage.").

⁴⁴ See, e.g., Thomas H. Murray, Genetic Exceptionalism and "Future Diaries": Is Genetic Information Different from Other Medical Information?, in GENETIC SECRETS 60, 71 (Mark A. Rothstein ed., 1997) ("Genetic information is special because we are inclined to treat it as mysterious, as having exceptional potency or significance, not because it differs in some fundamental way from all other sorts of information about us.").

⁴⁵ This example comes from Sonia M. Suter, *The Allure and Peril of Genetics Exceptionalism:* Do We Need Special Genetics Legislation?, 79 WASH. U. L.Q. 669, 715–21 (2001).

⁴⁶ See generally Media Release, National Breast and Ovarian Cancer Centre, Risk of Invasive Breast Cancer in Women Exposed to Diethylstilbestrol in Utero: A Review of the Evidence (Feb. 2008), http://www.nbcc.org.au/media/DES_statement.html.

⁴⁷ Luck egalitarianism offers a formalization of this concept. *See generally* Nir Eyal, *Egalitarian Justice and Innocent Choice*, J. ETHICS & SOC. PHIL., Jan. 2007, at 1–2, http://www.jesp.org/PDF/Egal_Justice.pdf (describing luck egalitarianism). Eyal suggests a modified version of luck egalitarianism, *id.* at 6–7, that would support equivalence of the genetic and nongenetic cases.

⁴⁸ See Bernstein, supra note 2, at 258-60.

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discrimination, but lawmakers do not know how severe discrimination would have been: it might have flourished if left checked only by existing laws, or social norms might have endured and held it largely at bay. This uncertainty makes GINA premature.

As to the other potential benefit, legislation may do little to reduce fear of discrimination. Though the antidiscrimination provisions may have symbolic value, 49 a comparative analysis of states with and without such laws reveals no difference in fearfulness.⁵⁰ Indeed, GINA could legitimate fears of genetic discrimination.⁵¹ For example, it may reduce research participation: privacy worries deter potential participants,⁵² vet GINA adds no safeguards for genetic information used in research and might exacerbate worries by increasing the perceived importance of that information. Also, because people already overestimate the problem,⁵³ heightened awareness due to GINA will likely worsen this misconception rather than increase understanding.

The costs of Title I — increased inequality, legislative complacency, and damage to the insurance system — overshadow the small benefits. Coverage and rate determinations do not include genetic factors but do incorporate uncontrollable nongenetic factors, such as environmental hazards. These nongenetic factors disproportionately affect lower socioeconomic classes, while genetic predispositions to disease occur fairly evenly in the population.⁵⁴ Since the health problems of the wealthy include a higher proportion of genetic conditions, the little increase in healthcare access that Title I provides also likely widens the gap between rich and poor.⁵⁵ Additionally, GINA might impede future progress in healthcare coverage by diminishing the drive to invest time and political capital in legislation that would close this gap.⁵⁶

⁴⁹ See, e.g., Mark A. Rothstein, Is GINA Worth the Wait?, 36 J.L. MED. & ETHICS 174, 177 (2008) (noting the symbolic value of declaring a policy against genetic discrimination).

⁵⁰ See Mark A. Hall & Stephen S. Rich, Patients' Fear of Genetic Discrimination by Health Insurers: The Impact of Legal Protections, 2 GENETICS MED. 214, 219-20 (2000) (using comparative case study analysis to find that "[I]egal protections have had little impact on the perceived risks of genetic discrimination" and doubting that federal legislation would solve the problem).

⁵¹ See Greely, supra note 3, at 867 ("[T]he mere fact that Congress has passed legislation against genetic discrimination might have the perverse effect of convincing the public that the risk of discrimination is actually high."); Suter, supra note 45, at 740-41 ("By responding to the public's fears with special protections for genetic information, genetics legislation may validate and fuel the flames of these fears as well as the underlying perspective [of genetic exceptionalism] that generates those fears. Moreover, it tends to stigmatize genetic information by suggesting that it warrants special protections." (footnote omitted)).

⁵² See sources cited supra note 3.

See Bernstein, supra note 2.

See Suter, supra note 45, at 719-21.

 $^{^{55}}$ See id. at 727-37 (arguing that disparate impact of genetic antidiscrimination legislation on the poor should invalidate that legislation).

⁵⁶ See Chetan Gulati, Genetic Antidiscrimination Laws in Health Insurance: A Misguided Solution, 4 QUINNIPIAC HEALTH L.J. 149, 151 (2001) ("[G]enetic antidiscrimination laws remove

though GINA may provide expedient incremental reform,⁵⁷ it weakens support for *further* reform. The poor may be less able to press for incremental extensions of coverage predominantly to their benefit, and those supporters of the general extension of healthcare whose motivations included personal fear of inadequate coverage for genetic conditions may decrease or, on the margin, withhold their support. To the extent that GINA satisfies the politically active middle and upper classes, it may reduce their desire to lobby for healthcare reform, leaving the lower class without the power to gain extensions of coverage for its members.⁵⁸ GINA increases inequality and may help mire federal healthcare legislation in that condition.

In addition, GINA may undermine the efficiency of the health insurance system. GINA affirms the use of a market-based insurance system, but such a system depends on the free use of information for Otherwise, adverse selection hobbles insurers; maximal efficiency. people who know their high genetic risks buy more insurance, but insurers cannot change prices to reflect that risk.⁵⁹ GINA overloads the market by giving it a task for which it is poorly suited: increasing healthcare coverage. By proscribing use of genetic information, GINA will force insurers either to discriminate indirectly — perhaps by offering limited plans unappealing to people with known genetic risks — or to raise all premiums to reflect the increased risk of those people. Higher premiums would deter people with lower expected medical costs from buying insurance, which in turn would cause premiums to spiral even higher. These consequences will grow only more severe as additional genetic tests become available. By undermining the market-based health insurance system without offering a substitute, such as mandatory health insurance or universal health coverage, GINA may decrease coverage through systemic inefficiency.⁶⁰

In contrast, the benefits of Title II appear greater and its costs less severe. It seems possible that the problem of genetic discrimination by

a powerful argument for replacing the commercial health insurance system with a social insurance system."); id. at 204–10.

⁵⁷ See, e.g., Susan M. Wolf & Jeffrey P. Kahn, Genetic Testing and the Future of Disability Insurance: Ethics, Law & Policy, 35 J.L. MED. & ETHICS (SPECIAL SUPPLEMENT) 6, 9 (2007).

⁵⁸ See Suter, supra note 45, at 725–27; cf. Colin S. Diver, Policymaking Paradigms in Administrative Law, 95 HARV. L. REV. 393, 430–31 (1981) (arguing that "incrementalism can succeed only as long as its remedial apparatus functions smoothly," and that "[t]he remedial character of incrementalism is nullified if the interests harmed at one stage lack the resources to seek later relief").

⁵⁹ For an overview of adverse selection, see generally George A. Akerlof, *The Market for "Lemons": Quality Uncertainty and the Market Mechanism*, 84 Q.J. ECON. 488 (1970). For a discussion of adverse selection and actuarial fairness — people paying insurance prices equivalent to their known risks — see Onora O'Neill, *Genetic Information and Insurance: Some Ethical Issues*, 352 PHIL. TRANSACTIONS ROYAL SOC'Y B 1087, 1087–90 (1997).

⁶⁰ This market effect, if large enough, could also worsen socioeconomic disparity by pricing the poor out of the insurance market entirely.

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employees is larger. At a minimum, unlike in insurance, incidents of intrusive, nonconsensual genetic testing have come to light in the employment context.⁶¹ When such a practice appears, GINA provides a clear cause of action against the employer and a set of minimum penalties, which may both deter more employers from genetic discrimination and assist particular litigants. In addition, legislation may reinforce the idea that employers should not make their employment decisions based on health conditions. Furthermore, the costs of Title II appear smaller. There is less direct use of nongenetic factors in employment assessments, which generally do not include environmental factor questionnaires, so the fairness and equality problems stemming from differential treatment of genetic and nongenetic factors may be reduced in the employment context.62 Also, especially since the Americans with Disabilities Act⁶³ bars discrimination against some with manifested health conditions, 64 additional legislation barring nongenetic health condition discrimination would likely be seen as an incremental step toward improving employment policy; in the field of health insurance, such a step would undermine the foundation of the free-market insurance system. And while many do call for fundamental changes to the health insurance system, such as universal coverage,65 no widely supported employment reforms propose such a drastic change. Thus, the GINA employment provisions serve to tweak and refine an existing antidiscrimination system without inhibiting larger potential changes.

Passing antidiscrimination legislation for genes, but not for uncontrollable nongenetic factors, seems at best an unfinished job. Although this incomplete legislation offers a small step toward better employment discrimination policy, it hinders bigger health insurance changes as well as the realization that the genetic causes of some diseases do not necessarily make them more worthy of concern. With the passage of the GINA health insurance provisions, legislators and the public now need to avoid complacency and continue pushing toward GINA's underlying goal of expanding access to healthcare coverage.

⁶¹ See Porter, supra note 11, at 72. Perhaps the greater number of employers, most of whom deal with a smaller number of people than do health insurers, enables them both to have a wider range of policies on genetic information and to hide their behavior more easily.

⁶² Of course, discrimination based on evidence of lower class status in general still exists, but that discrimination is not particularly health-centered.

^{63 42} U.S.C. §§ 12101–12213 (2000).

⁶⁴ See id. § 12102(2) (defining "disability" as "a physical or mental impairment that substantially limits one or more of the major life activities").

⁶⁵ See Gulati, supra note 56, at 155 ("On at least five separate occasions in the last century there has been a concerted social movement . . . to design and pass a universal health insurance scheme.").