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## Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act

Jessica L. Roberts

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# Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act

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Jessica L. Roberts

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*The Genetic Information Nondiscrimination Act ("GINA"), enacted in May 2008, protects individuals against discrimination by insurance companies and employers on the basis of genetic information. GINA is not only the first civil rights law of the new millennium, but it is also the first preemptive antidiscrimination statute in American history. Traditionally, Congress has passed retrospective antidiscrimination legislation, reacting to existing discriminatory regimes. However, little evidence indicates that genetic-information discrimination is currently taking place on a significant scale. Thus, unlike the laws of the twentieth century, GINA attempts to eliminate a new brand of discrimination before it takes hold. This Article provides a detailed look at this unprecedented new statute, beginning with its initial introduction in 1995. Next, the Article examines the justifications for passing preemptive genetic-information discrimination legislation, concluding that Congress had twin objectives: a research justification and an antidiscrimination justification. Lastly, the Article explores the implications of passing antidiscrimination legislation absent a history of discrimination. It concludes that GINA's preemptive nature may be both its greatest attribute and its deepest flaw.*

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# Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act

*Jessica L. Roberts\**

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\* Assistant Professor of Law, University of Houston Law Center. Thank you to Bruce Ackerman, Rick Bales, Bill Corbett, Liz Emens, Philip Hamburger, Melissa Hart, David Hess, Kevin Roberts, Michael Stein, Kim Yuracko, the participants of the Law and Society Association's Panel on Work, Disability, and Genetic Information, and the participants of the Associates' Workshop at Columbia University, in particular Bertrall Ross and Samuel Bray. Many thanks also to my outstanding editors and cite-checkers at the VANDERBILT LAW REVIEW: Benjamin Raybin, Ryan Holt, Elizabeth Fisher, Ashley Bassel, Jennifer Bennett, Barbara Barreno, David Barnes, Michael Bowers, Laura Carlisle, Michael Johnson, and Nancy Zeronda. I completed this project as an Associate-in-Law at Columbia Law School.

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## INTRODUCTION

In May 2008, Congress passed the Genetic Information Nondiscrimination Act (“GINA”),<sup>1</sup> the first major American antidiscrimination statute in over a decade. While characterized as civil rights legislation, GINA represents a major departure from every antidiscrimination statute preceding it.

Historically, antidiscrimination law has been Janus-like, one face reflecting upon a legacy of discrimination with the other gazing forward to stop discrimination in the future. The four major employment discrimination statutes prior to GINA—Title VII of the Civil Rights Act, the Age Discrimination in Employment Act, the Rehabilitation Act, and the Americans with Disabilities Act—were all *retrospective*: each looked to discrimination in the past to justify protection in the present and the future.

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1. Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (2008).

Conversely, GINA has little upon which to reflect. GINA prohibits health insurers and employers from making decisions based on genetic information. While some examples do exist, both GINA's advocates and adversaries agreed that scant evidence indicated a significant history of genetic-information discrimination. Thus, whereas the preceding laws were retrospective, GINA is *preemptive*. It anticipates a form of discrimination that may pose a future threat. GINA's opponents cited the lack of existing genetic-information discrimination as evidence that the law was premature or unnecessary. Its proponents, however, presented GINA as a unique opportunity to stop discrimination before it starts. It is this preemptive nature, basing protection on future—rather than past or even present—discrimination, that truly makes GINA novel.

Novelty aside, preemptive antidiscrimination legislation has its benefits and its drawbacks. By passing GINA before genetic-information discrimination could take hold, Congress may have effectively bypassed a new variety of discriminatory treatment. GINA's ability to preempt discrimination is perhaps its greatest strength. Yet the statute's preemptive qualities carry with them potentially serious hurdles regarding GINA's enforcement and effectiveness. In particular, its preemptive nature may call into question Congress's authority to pass antidiscrimination legislation without an existing history of discrimination. Moreover, if genetic-information discrimination never becomes a widespread problem, we will never know whether GINA was wildly successful or totally unnecessary. Depending upon how these issues are resolved, GINA may represent the first and last effort at preempting discrimination. As time passes, it will become clearer whether preemptive legislation has a role in the future of antidiscrimination law or whether GINA is merely a fascinating exception to the time-honored tradition of retrospective lawmaking.

This Article analyzes GINA as the first preemptive antidiscrimination statute in American history. It proceeds in four parts. Part I traces the evolution of GINA from its introduction in 1995 to its passage in May 2008. Part II differentiates GINA from the four retrospective employment discrimination statutes preceding it. Part III examines the justifications for enacting preemptive genetic antidiscrimination legislation. Finally, Part IV explores the strengths and weaknesses of preemptive antidiscrimination legislation.

## I. THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008

GINA is the culmination of more than two-dozen proposed bills and over a decade of legislative debate. This Part begins with the background of the law, examining what prompted members of Congress to begin their thirteen-year push for a genetic antidiscrimination statute. Next, it provides a brief overview of GINA's lengthy legislative history. It concludes with a close reading of the statute, highlighting the similarities and differences between the law's two substantive sections.

### A. Background

Congress passed GINA in response to scientific advancements that advocates feared could result in a new form of discrimination, left uncovered by existing legal protections.

#### 1. Scientific Background

Genetic-information discrimination is a relatively young concept, which traces its roots to major scientific developments within the last two decades. In 1990, scientists began the Human Genome Project ("HGP"), a thirteen-year effort to sequence the human genome, coordinated and funded by the U.S. Department of Energy and the National Institutes of Health.<sup>2</sup> Among its goals were identifying the protein-coding bases of the human genome; sequencing the over three billion chemical base pairs that comprise human DNA; inputting this information into publically available databases; and addressing the potential ethical, legal, and social issues that might result.<sup>3</sup> Researchers released the results of the HGP in April 2003.<sup>4</sup> At present, over one thousand genetic tests are available.<sup>5</sup> Scientists hoped that studying the human genome would lead to a better understanding of genetically linked health conditions, including

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2. Oak Ridge National Laboratory, Human Genome Project Information, [http://www.ornl.gov/sci/techresources/Human\\_Genome/home.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/home.shtml) (last visited Jan. 23, 2009).

3. *Id.*

4. Oak Ridge National Laboratory, Major Events in the U.S. Human Genome Project and Related Projects, [http://www.ornl.gov/sci/techresources/Human\\_Genome/project/timeline.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/project/timeline.shtml) (last visited Jan. 23, 2009).

5. NANCY LEE JONES & AMANDA K. SARATA, CONGRESSIONAL RESEARCH SERVICE REPORT FOR CONGRESS, NO. RL34584, THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008 (GINA) 2 (updated Oct. 8, 2008), available at <http://fpc.state.gov/documents/organization/108319.pdf> (noting that as of May 29, 2008, 1,271 clinical genetic tests were available).

diabetes, heart disease, Parkinson's disease, bipolar disorder, and asthma.<sup>6</sup>

Supporters of GINA believed that, while these scientific advancements might alter the way in which we understand and treat disease, they would also create new ways to discriminate.<sup>7</sup> Since the mid-nineties, proponents of genetic antidiscrimination legislation cited the HGP to demonstrate that the United States needs legal protections for genetic information.<sup>8</sup> GINA's advocates maintained that the existing antidiscrimination regime was not equipped to deal with this novel form of discrimination.

## 2. Legal Background

Although the idea of genetic-information discrimination is relatively new, potential victims had limited federal and state protections—both in health insurance and in employment—prior to GINA.

With regard to health insurance, the Health Insurance Portability and Accountability Act ("HIPAA") prohibits group health insurers from using genetic information in determining eligibility or setting premiums and from treating genetic information as a preexisting condition.<sup>9</sup> While these provisions protect individuals within the group, HIPAA does not prevent health insurers from using genetic information in deciding whether to accept the group as a whole or in setting the group's premium.<sup>10</sup> HIPAA, therefore, applies to discrimination against *individual* members of the group but does little to prevent discrimination against the group in its entirety. Additionally, the law does not prohibit group health insurers from requesting genetic information or requiring genetic testing.<sup>11</sup> Moreover, HIPAA does not apply to individual health insurance

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6. *Id.* at 1. At present scientists have discovered links between genetic mutations and over 6,000 disorders, such as cystic fibrosis, sickle cell anemia, Alzheimer's disease, and multiple cancers. Carolyne Park, *Genetics Offers Tool in Combat of Cancer: Field Young, Pays Off in Early Detection*, ARK.-DEMOCRAT GAZETTE, Aug. 24, 2008, at 1.

7. *See, e.g., id.*

8. *See, e.g.*, 141 CONG. REC. H14,906 (daily ed. Dec. 14, 1995) (statement of Rep. Slaughter) (introducing H.R. 2748).

9. Health Insurance Portability and Accountability Act of 1996, 29 U.S.C. §§ 1181–82 (2006), 42 U.S.C. §§ 300gg-41 (2006). Congress enacted the Health Insurance Portability and Accountability Act in 1996. Title I protects health insurance for workers and their families when they change or lose jobs by amending Employee Retirement Income Security Act (ERISA), the Public Health Service Act (PHSA), and the Internal Revenue Code (IRC). Title II, the Administrative Simplification section, establishes national healthcare standards.

10. JONES & SARATA, *supra* note 5, at 5.

11. *Id.*



policies.<sup>12</sup> Perhaps most importantly, HIPAA offers no protection outside of health insurance, allowing employers—the providers of health insurance for millions of working Americans<sup>13</sup>—to use genetic information in their hiring, firing, and promotion decisions.

Federal law also prevented employment discrimination based on certain genetic conditions pre-GINA. Title I of the Americans with Disabilities Act forbids employers from discriminating against a qualified individual on the basis of a disability in hiring, promotion, training, and other job-related decisions.<sup>14</sup> The Act defines a disability as “(a) a physical or mental impairment that substantially limits one or more major life activities of such individual; (b) a record of such an impairment; or (c) being *regarded as* having such an impairment.”<sup>15</sup> Thus, although Title I never explicitly mentions genetic information, it may cover a person who experiences an adverse employment action based on her genetic information (even if she has not manifested an impairment) if her employer *regards her as* having a disability.<sup>16</sup>

Proponents of GINA feared that the Supreme Court’s limited interpretation of what constituted “disability” at the time would not adequately protect genetic information.<sup>17</sup> In *Sutton v. United Air*

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12. *Id.*

13. *See id.*

14. Americans with Disabilities Act, Title I, 42 U.S.C. § 12112(a) (2006) (“No covered entity shall discriminate against a qualified individual on the basis of disability in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment.”).

15. 42 U.S.C. § 12102(1) (emphasis added).

16. Several sources support the position that the ADA protects against genetic-information discrimination in employment. For example, the EEOC initially interpreted the ADA as covering genetic information. EQUAL EMPLOYMENT OPPORTUNITY COMM’N, 2 COMPLIANCE MANUAL § 902 (1995). Similarly, EEOC Commissioner Paul Miller has noted that Title I “can be interpreted to prohibit employment discrimination based on genetic information. However, the ADA does not explicitly address the issue and its protections are limited and uncertain.” *Genetic Information in the Workplace: Hearing on S.1332 Before the Sen. Comm. on Health, Educ., Labor, & Pensions*, 106th Cong. 1 (2000) (statement of Commissioner Paul Steven Miller, Equal Employment Opportunity Commission) [hereinafter Statement of Paul Steven Miller]. But perhaps most tellingly, when a potential claimant filed with the EEOC, alleging genetic-information discrimination, the Commission issued a determination that its investigation supported her claim pursuant to the ADA. (I discuss this case at greater length in Section II. *See infra* Section II(B)(1)(a).) That said, as of the passing of GINA, no reported cases held that the ADA covered genetic-information discrimination. JONES & SARATA, *supra* note 5, at 7.

17. *See, e.g., Protecting Against Genetic Discrimination: The Limits of Existing Laws: Hearing Before the S. Comm. on Health, Educ., Labor, and Pensions*, 107th Cong. 2 (2002) (testimony of Andrew J. Imparato, President and CEO of the American Association of People with Disabilities):

[T]he ADA as drafted does provide some protections against genetic discrimination in employment, but the law has been interpreted by the Supreme Court and lower federal courts in a manner which weakens its protections. Whereas the ADA can be and has been used to stop genetic

*Lines*, the Supreme Court held that being “regarded as” having a disability applied only to two specific circumstances: (1) a mistaken belief that a person has a limiting impairment, or (2) a mistaken belief that a nonlimiting impairment substantially limits major life activities.<sup>18</sup> Neither situation covered discrimination based on valid genetic information. If an employer fires someone because of a genetic proclivity for cancer, that action does not result from the mistaken belief that the person actually *has* cancer or the mistaken belief that the person’s genetic information limits her current performance of major life activities.

On September 25, 2008—four months after signing GINA—President George W. Bush signed the Americans with Disabilities Act Amendments Act of 2008.<sup>19</sup> The amendments, which went into effect January 1, 2009, reject the Supreme Court’s limited interpretation of disability and restore the broad protections intended by Congress.<sup>20</sup> Had GINA been debated only a few months longer, the amendments could have weakened the claim that existing antidiscrimination laws failed to protect genetic information. Additionally, another federal statute, Title VII, may extend to genetic information—but only when that information is linked to a particular protected group.<sup>21</sup>

The Executive Branch also protected genetic information before GINA. President Clinton issued an executive order on February 8,

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discrimination in some instances, the protections it affords offer little security to people with genetic markers and health conditions that have not yet developed into full-blown debilitating conditions.

Imparato is referring to the United States Supreme Court case *Sutton v. United Air Lines*, 527 U.S. 471 (1999) and its progeny. The Supreme Court held that the ADA applies only to unmitigated impairments. *Id.* at 488. Yet more importantly to genetic-information discrimination, the Court also limited what constituted being “regarded as” having a disability. See *infra* note 20 and accompanying text.

18. *Sutton*, 527 U.S. at 489 (restricting being “regarded as” having a disability to two circumstances: “(1) a covered entity mistakenly believes that a person has a physical impairment that substantially limits one or more major life activities, or (2) a covered entity mistakenly believes that an actual, nonlimiting impairment substantially limits one or more major life activities”). The Court noted: “In both cases, it is necessary that a covered entity entertain misperceptions about the individual—it must believe either that one has a substantially limiting impairment that one does not have or that one has a substantially limiting impairment when, in fact, the impairment is not so limiting.” *Id.*

19. Americans with Disabilities Act Amendments Act, Pub. L. No. 110-325, 122 Stat. 3553 (2008).

20. *Id.* § 2(a)(4) (finding that “the holdings of the Supreme Court in *Sutton v. United Air Lines, Inc.*, 527 U.S. 471 (1999) and its companion cases have narrowed the broad scope of protection intended to be afforded by the ADA, thus eliminating protection for many individuals whom Congress intended to protect”).

21. See, e.g., *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260 (9th Cir. 1998) (holding that blood tests for sickle cell violated Title VII). *Norman-Bloodsaw* is, however, the only case of this kind.

2000 forbidding genetic-information discrimination against federal employees.<sup>22</sup> The Executive Order on Genetic Discrimination prohibits federal departments and agencies from firing, failing to hire, limiting, segregating, classifying, or otherwise discriminating against their employees and potential employees on the basis of “protected genetic information.”<sup>23</sup> It also proscribes departments and agencies from acquiring or disclosing “protected genetic information,” except under special circumstances.<sup>24</sup> The Order defines “protected genetic information” as “(A) information about an individual’s genetic tests; (B) information about the genetic tests of an individual’s family members; or (C) information about the occurrence of a disease, or medical condition or disorder in family members of the individual.”<sup>25</sup> Congress would adopt a very similar definition when passing GINA over eight years later.<sup>26</sup>

In addition to the federal measures, several pre-GINA state statutes protected against genetic-information discrimination in both health insurance<sup>27</sup> and employment.<sup>28</sup> Yet the state laws are limited in scope, as ERISA’s preemption provision exempts self-funded, employer-provided private health insurance from state insurance laws.<sup>29</sup> Over half of covered Americans are insured through these

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22. Exec. Order No. 13,145, 65 Fed. Reg. 6,877 (Feb. 8, 2000).

23. *Id.* §§ 1-202(a), (b).

24. *Id.* §§ 1-202(c), (d).

25. *Id.* § 1-201(e)(1).

26. *See infra* note 83.

27. As of January 2008, forty-eight states and the District of Columbia have enacted laws prohibiting certain uses of genetic information by health insurers. NAT’L CONFERENCE OF STATE LEGISLATURES, GENETICS AND HEALTH INSURANCE STATE ANTI-DISCRIMINATION LAWS (2008), <http://www.ncsl.org/programs/health/genetics/ndishlth.htm>. Mississippi and Pennsylvania lack statutes on this issue. Alabama prohibits denying coverage to people with the sickle cell trait and considering a predisposition for cancer in risk assessment but allows other considerations of genetic information. *Id.* Washington’s statute only prevents the disclosure of genetic information without consent, thereby allowing the use of genetic information in eligibility determinations. *Id.* Most of the laws apply to both group and individual insurance policies, while some states cover only one or the other. *Id.* Many, but not all, prohibit insurers from requiring genetic testing or genetic information. *Id.*

28. States first began protecting against genetic-information discrimination in the 1970s and 80s by outlawing discrimination based on the sickle cell trait. NAT’L CONFERENCE OF STATE LEGISLATURES, STATE GENETICS EMPLOYMENT LAWS (2008), <http://www.ncsl.org/programs/health/genetics/ndiscrim.htm>. In 1991, Wisconsin became the first state to prohibit genetic testing and discrimination at work. *Id.* As of January 2008, thirty-four states and the District of Columbia outlawed employment discrimination based on genetic information. *Id.* However, the range of the law varies. All the laws cover discrimination based on the results of genetic tests, and several include inherited characteristics, but may not include family members’ genetic test results or family history. *Id.* Some states include safety exceptions, allowing employers to use genetic information when identifying potential workplace hazards. *Id.*

29. 29 U.S.C. § 1144 (2006).

types of plans,<sup>30</sup> making preemption a serious obstacle to enforcing state statutes that prohibit genetic-information discrimination in health insurance.

Yet despite the protections for genetic information that existed at the time, GINA's advocates argued that those safeguards were ultimately inadequate, urging Congress to pass a comprehensive federal statute.

### *B. Legislative History*

Before passing almost unanimously, GINA endured a thirteen-year odyssey through Congress. In 1994, members of the 103rd Congress first considered the issue of genetic-information discrimination as part of national healthcare reform.<sup>31</sup> The next term, several members introduced bills specifically prohibiting discrimination based on genetic information.<sup>32</sup> Among the six bills introduced between 1995 and 1996, the Genetic Information Nondiscrimination in Health Insurance Act of 1995, sponsored by Representative Louise Slaughter, won the most support with seventy-six cosponsors.<sup>33</sup> However, the companion bill in the Senate, sponsored by Senator Olympia Snowe, had only one cosponsor.<sup>34</sup> Although Slaughter's bill died at the end of the 104th Congress, its supporters remained tenacious: both Representative Slaughter—a microbiologist with a Masters in Public Health<sup>35</sup>—and Senator Snowe would fight for genetic antidiscrimination legislation in each subsequent Congress until GINA passed.

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30. Wendy K. Mariner, *Can Consumer-Choice Plans Satisfy Patients? Problems with Theory and Practice in Health Insurance Contracts*, 69 BROOK. L. REV. 485, 489 (2004).

31. S. Rep. No. 108-122, at 13 (2003).

32. The genetic antidiscrimination bills introduced in the 104th Congress were: the Genetic Confidentiality and Nondiscrimination Act of 1996, S. 1898, 104th Cong. (1996) (sponsored by Sen. Pete Domenici); the Genetic Information Nondiscrimination in Health Insurance Act of 1995, S. 1694, 104th Cong. (1996) (companion bill to H.R. 2748) (sponsored by Sen. Olympia Snowe); the Genetic Fairness Act of 1996, S. 1600, 104th Cong. (1996) (sponsored by Sen. Dianne Feinstein); the Genetic Information Nondiscrimination in Health Insurance Act of 1995, H.R. 2748, 104th Cong. (1995) (sponsored by Rep. Louise Slaughter); the Genetic Privacy and Nondiscrimination Act of 1995, S. 1416, 104th Cong. (1995) (sponsored by Sen. Mark Hatfield); and the Genetic Privacy and Nondiscrimination Act of 1995, H.R. 2690, 104th Cong. (1995) (companion bill to S. 1416) (sponsored by Rep. Clifford Stearns).

33. Genetic Information Nondiscrimination in Health Insurance Act of 1995, H.R. 2748, 104th Cong. (1995) (list of cosponsors, available at <http://thomas.loc.gov/cgi-bin/bdquery/z?d104:HR02748:@@P>).

34. Genetic Information Nondiscrimination in Health Insurance Act of 1995, S. 1694, 104th Cong. (1996) (list of cosponsors, available at <http://thomas.loc.gov/cgi-bin/bdquery/z?d104:SN01694:@@P>).

35. Jonathan D. Rockoff, *Senate Protects Genetic Test Data*, BALT. SUN, Apr. 25, 2008, at 1A.

In the following years, members of the House and Senate introduced multiple bills prohibiting genetic-information discrimination each term: seven bills in the 105th Congress,<sup>36</sup> three in the 106th,<sup>37</sup> four in the 107th,<sup>38</sup> five in the 108th,<sup>39</sup> two in the 109th,<sup>40</sup> and two in the 110th.<sup>41</sup> Yet despite hundreds of cosponsors,<sup>42</sup> term after term, opponents managed to stop the bills in the House.<sup>43</sup> The

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36. The bills of the 105th Congress were: the Genetic Protection in Insurance Coverage Act, H.R. 2216, 105th Cong. (1997) (sponsored by Rep. Joseph P. Kennedy); the Genetic Privacy and Nondiscrimination Act of 1997, H.R. 2198, 105th Cong. (1997) (sponsored by Rep. Clifford Stearns); the Genetic Confidentiality and Nondiscrimination Act of 1997, S. 422, 105th Cong. (1997) (sponsored by Sen. Pete Domenici); the Genetic Information Nondiscrimination in Health Insurance Act Of 1997, S. 89, 105th Cong. (1997) (companion bill to H.R. 306) (sponsored by Sen. Olympia Snowe); the Genetic Information Health Insurance Discrimination Act of 1997, H.R. 328, 105th Cong. (1997) (sponsored by Rep. Gerald Solomon); the Genetic Information Nondiscrimination in Health Insurance Act of 1997, H.R. 306, 105th Cong. (1997) (sponsored by Rep. Louise Slaughter); and the Genetic Privacy and Nondiscrimination Act of 1997, H.R. 341, 105th Cong. (1997) (sponsored by Rep. Clifford Stearns).

37. The 106th Congress had three bills introduced: H.R. Res. 520, 106th Congress (2000) (sponsored by Rep. Louise Slaughter) ("Providing for consideration of the bill (H.R. 2457) to prohibit health insurance and employment discrimination against individuals and their family members on the basis of predictive genetic information or genetic services."); the Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, H.R. 2457, 106th Cong. (1999) (sponsored by Rep. Louise Slaughter); the Genetic Information Nondiscrimination in Health Insurance Act of 1999, S. 543, 106th Cong. (1999) (sponsored by Sen. Olympia Snowe).

38. The four bills of the 107th Congress were: the Genetic Information Nondiscrimination in Health Insurance Act of 2001, S. 382, 107th Cong. (2001) (sponsored by Sen. Olympia Snowe); the Genetic Nondiscrimination in Health Insurance and Employment Act, H.R. 602, 107th Cong. (2001) (sponsored by Rep. Louise Slaughter); the Genetic Nondiscrimination in Health Insurance and Employment Act, S. 318, 107th Cong. (2001) (sponsored Sen. Thomas Daschle); and the Protecting Civil Rights for All Americans Act, S. 19, 107th Cong. Title IV (2001) (sponsored by Sen. Thomas Daschle) ("Providing for genetic nondiscrimination in health insurance and employment").

39. In the 108th Congress, there were five bills proposed: the Bipartisan Patient Protection Act of 2004, S. 2083, 108th Cong. (2004) (sponsored by Rep. Barbara Boxer); the Genetic Privacy and Nondiscrimination Act of 2003, H.R. 3636, 108th Cong. (2003) (sponsored by Rep. Clifford Stearns); the Genetic Information Nondiscrimination Act of 2003, S. 1053, 108th Cong. (2003) (sponsored by Sen. Olympia Snowe); H.R. 1910, 108th Cong. (2003) (sponsored by Rep. Louise Slaughter); the Equal Rights and Equal Dignity for Americans Act of 2003, S. 16, 108th Cong. (2003) (sponsored by Sen. Thomas Daschle).

40. The 109th Congress only proposed two bills: the Genetic Information Nondiscrimination Act of 2005, H.R. 1227, 109th Cong. (2005) (sponsored by Rep. Judy Biggert) and the Genetic Information Nondiscrimination Act of 2005, S. 306, 109th Cong. (2005) (sponsored by Sen. Olympia Snowe).

41. Representative Slaughter introduced the Genetic Information Nondiscrimination Act of 2008, H.R. 493, 110th Cong. (2007), which would eventually become GINA, and Senator Snowe introduced the Genetic Information Nondiscrimination Act of 2007, S. 358, 110th Cong. (2007).

42. For example, Representative Slaughters' bills H.R. 1910 and H.R. 306 had 242 and 213 cosponsors, respectively. H.R. 1910, 108th Cong. (2003); the Genetic Information Nondiscrimination in Health Insurance Act of 1997, H.R. 306, 105th Cong. (1997).

43. Jerry Zremski, *Bush Signs Genetic Bias Bill into Law*, BUFFALO NEWS, May 22, 2008, at A1 (quoting Sharon Terry, President of the Genetic Alliance).

strongest opposition came from the business community, which feared that the proposed laws would increase litigation as well as bar insurers from recommending potentially life-saving genetic tests.<sup>44</sup> The Genetic Information Nondiscrimination in Employment Coalition (“GINE Coalition”), a business group that included the Society for Human Resource Management, the Chamber of Commerce, and the National Association of Manufacturers, was among the most powerful groups contesting legislation.<sup>45</sup> Despite bipartisan support,<sup>46</sup> genetic antidiscrimination advocates believed that the Republican leadership in the House was responsible for failing to push the bills to the floor.<sup>47</sup> When the Democrats won control in the 2006 interim election, supporters of the legislation hoped the switch in party control would finally bring the legislation to a vote.

On January 16, 2007, with over a hundred cosponsors, Representative Slaughter introduced the Genetic Information Nondiscrimination Act of 2007.<sup>48</sup> A few months later, the bill passed

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44. Judith Graham, *Senate: DNA Bias Not Legal; House Expected to Pass Ban on Use of Genetic Profiles Against Workers*, CHI. TRIB., Apr. 25, 2008, at C1 (“Opposition to the legislation came largely from the business community, which was concerned about potential law suits and financial liability for technical errors, among other issues.”); *Why It Matters*, SAN JOSE MERCURY NEWS, Sept. 30, 2007 (“[According to its opponents,] the measure could cause businesses big problems. Among other things, employers fear it would subject them to numerous lawsuits and insurers say they could be barred from recommending genetic tests that could enable people to get life-saving treatments.”).

45. *Protecting Workers from Genetic Discrimination: Hearing Before H. Subcomm. on Health, Employment, Labor and Pensions of the H. Comm. on Energy and Commerce*, 110th Cong. 110-1 (2007) (statement of Burton J. Fishman, Counsel to GINE Coalition) [*hereinafter* Statement of Burton J. Fishman].

46. Since the beginning of his presidency, President George W. Bush spoke out against genetic discrimination:

Genetic discrimination is unfair to workers and their families. It is unjustified. To deny employment or insurance to a healthy person based only on a predisposition violates our country's belief in equal treatment and individual merit. In the past, other forms of discrimination have been used to withhold rights and opportunities that belong to all Americans. Just as we have addressed discrimination based on race, gender and age, we must now prevent discrimination based on genetic information.

*Genetic Information in the Workplace: Hearing on S.1332 Before the S. Comm. on Health, Educ., Labor, and Pensions*, 106th Cong. (2001) (testimony of Dr. Francis S. Collins, Director of National Human Genome Research Institute) (quoting President George W. Bush), available at <http://www.genome.gov/10003482>. Moreover, members of both parties often cosponsored or voted for the genetic-information discrimination bills.

47. See Zremski, *supra* note 43.

48. Genetic Information Nondiscrimination Act of 2007, H.R. 493, 110th Cong. (2007) (listing cosponsors), available at <http://thomas.loc.gov/cgi-bin/bdquery/z?d110:HR00493:@@P>.

the House with a vote of 420-3.<sup>49</sup> However, Senator Tom Coburn, a medical doctor from Oklahoma—nicknamed “Dr. No” for his holds on numerous bills up for unanimous consent<sup>50</sup>—put a hold on Representative Slaughter’s bill.<sup>51</sup> Senator Coburn was concerned that the bill could subject employers to employment discrimination suits because of disputes over health insurance coverage.<sup>52</sup> According to this scenario, someone who has a genetic-information discrimination claim for health insurance might assert that the same conduct underlying the health insurance claim also qualifies as employment discrimination. Senator Coburn feared that employers who provide their own health insurance could be sued twice under GINA,<sup>53</sup> “‘creat[ing] a trial lawyer’s bonanza.’”<sup>54</sup> It therefore appeared that yet another genetic antidiscrimination bill might be stymied.

Eventually, a Democratic staffer from the House Energy and Commerce Committee proposed a solution: creating a “firewall” between the health insurance and employment parts of the bill to ensure that claimants could not sue under both provisions simultaneously to reap the benefits of the sections’ separate remedies.<sup>55</sup> The firewall prohibits employment discrimination claims for conduct that is actionable under GINA’s health insurance provisions.<sup>56</sup> After the Senate amended the bill to include the firewall, Senator Coburn let it go forward.<sup>57</sup>

Almost exactly a year after the House’s vote, the Senate passed the amended bill 95-0 on April 24, 2008.<sup>58</sup> The House then approved it

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49. See Genetic Information Nondiscrimination Act of 2007, H.R. 493, 110th Cong., available at <http://thomas.loc.gov/cgi-bin/bdquery/z?d110:HR00493:@@R> (providing chronology of major actions).

50. Zremski, *supra* note 43.

51. Chris Casteel, *When Your Genes Are the Enemy*, OKLAHOMAN, Aug. 18, 2007, at 1A.

52. Andrew Pollack, *Congress Near Deal on Genetic Test Bias Bill*, N.Y. TIMES, Apr. 23, 2008, at C1.

53. *Id.*

54. *Id.*

55. Zremski, *supra* note 43.

56. The firewall prevents the employment discrimination title of GINA from “provid[ing] for enforcement of, or penalties for, a violation of any requirement or prohibition applicable to any covered entity subject to enforcement for a violation under [the health insurance portion of the] Act.” Genetic Information Nondiscrimination Act of 2008, Pub. Law No. 110-233, 122 Stat. 881 § 209(b) (2008).

57. Amy Harmon, *Congress Passes Bill to Bar Bias Based on Genes*, N.Y. TIMES, May 2, 2008, at A1.

58. Genetic Information Nondiscrimination Act of 2007, H.R. 493, 110th Cong., available at <http://thomas.loc.gov/cgi-bin/bdquery/z?d110:HR00493:@@R> (providing chronology of major actions).

414-1 with Congressman Ron Paul as the lone dissenter.<sup>59</sup> On May 21, 2008, President George W. Bush signed GINA into law.<sup>60</sup> Thus, after thirteen years of false starts and near misses, Congress finally passed a genetic antidiscrimination statute.<sup>61</sup>

### *C. Provisions*

Having traced GINA's journey through Congress, I now turn to the text of the statute itself, examining how GINA's provisions relate to existing laws and to each other.

#### 1. Provisions of Titles I, II, and III

GINA includes three titles: Title I prohibits genetic-information discrimination in health insurance, Title II prohibits genetic-information discrimination in employment, and Title III contains miscellaneous provisions regarding severability and child labor. Each of the two substantive titles draws from existing statutes, making GINA both new and familiar.

##### *a. Title I*

Title I bars health insurers from using genetic information to determine coverage, eligibility, or premiums; from requesting or requiring genetic testing or genetic information; and from obtaining genetic information for underwriting purposes.<sup>62</sup> Additionally, individual insurers and issuers of supplemental Medicare coverage

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59. In explaining his failure to support the H.R. 493, Rep. Paul cited his support for federalism and individualized decision-making in healthcare. See 155 CONG. REC. 4100 (daily ed. Apr. 25, 2007) (statement of Rep. Paul).

60. Genetic Information Nondiscrimination Act of 2007, H.R. 493, 110th Cong. (chronology of major actions), available at <http://thomas.loc.gov/cgi-bin/bdquery/z?d110:HR00493:@@R.s>.

61. See Mark A. Rothstein, *Is GINA Worth the Wait?*, 36 J.L. MED. & ETHICS 174, 174 (2008):

[GINA] has been pending in Congress for twelve years, despite the support of the last two presidential Administrations and the National Institutes of Health. It has been the subject of extensive affirmative lobbying by academic medical centers, pharmaceutical and biotech companies, genetic disease advocacy groups, and civil rights organizations. It has overcome vehement objections by employers and insurers. Its final passage, however, has been thwarted by a few Congressional leaders, who have prevented enactment despite overwhelming bipartisan support in both houses of Congress.

62. Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 §§ 101-106 (2008).



cannot treat genetic information as a preexisting condition.<sup>63</sup> As with HIPAA, in lieu of drafting a new statute, Congress amended existing health insurance laws to provide unified protection against genetic-information discrimination.

Title I reflects the complicated nature of the American health insurance system. It fortifies and clarifies HIPAA's protections by amending the Employee Retirement Income Security Act of 1974 ("ERISA"),<sup>64</sup> the Public Health Services Act ("PHSA"),<sup>65</sup> and the Internal Revenue Code.<sup>66</sup> Title I also contains sections amending the Social Security Act ("SSA").<sup>67</sup> GINA, therefore, applies to the group plans covered by ERISA, the group and individual plans governed by the PHSA, churches under the Internal Revenue Code, and Medigap pursuant to the SSA.

### *b. Title II*

Title II prohibits employers from hiring, firing, classifying, or otherwise disadvantaging employees on the basis of genetic information, as well as from requesting, requiring, or purchasing genetic information.<sup>68</sup> Additionally, Title II prohibits discrimination by unions, employment agencies, and training programs.<sup>69</sup>

Like Title I, Title II draws from existing laws. For example, it defines "employee" and "employer" according to Title VII,<sup>70</sup> "state employee" and "state employer" according to the Government Employee Rights Act,<sup>71</sup> and "covered employee" and "employing office" according to the Congressional Accountability Act.<sup>72</sup> As with Title VII, claimants under Title II of GINA must file with the Equal Employment Opportunity Commission ("EEOC") before suing.<sup>73</sup>

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63. *Id.* § 102(b). As mentioned, HIPAA prohibits group insurers from treating genetic information as a preexisting condition. *Supra* note 9.

64. Genetic Information Nondiscrimination Act § 101.

65. *Id.* § 102.

66. *Id.* § 103.

67. *Id.* § 104.

68. *Id.* § 202.

69. *Id.* §§ 203–05.

70. *Id.* § 202(2)(A)(i), (2)(B)(i).

71. *Id.* § 202(2)(A)(ii).

72. *Id.* § 202(2)(A)(iii).

73. Under both Title VII and GINA, before suing, a victim of discrimination must first file a "Charge of Discrimination" with the EEOC. EEOC, Filing a Charge of Discrimination, <http://www.eeoc.gov/employees/charge.cfm> (last visited Mar. 2, 2010). If the EEOC chooses not to pursue the claim, it will issue the claimant a "Notice of Right to Sue," authorizing her to sue her employer. *Id.* Title VII and GINA claimants can also request the right to sue 180 days after first filing with the EEOC. EEOC, Filing a Lawsuit, <http://www.eeoc.gov/employees/lawsuit.cfm> (last

However, unlike Title VII, claimants cannot file disparate impact actions.<sup>74</sup> GINA, therefore, prohibits only explicit discrimination on the basis of genetic information.

Importantly, Title II also defines the limits of GINA's protections. For example, it includes the aforementioned "firewall provision," which provides that a claimant cannot simultaneously sue her employer and health insurer for health insurance violations (unless the employer independently violated Title II).<sup>75</sup> However, Title II does not preclude claims under other federal or state statutes offering equal or greater protection—including the ADA and the Rehabilitation Act of 1973.<sup>76</sup>

### *c. Title III*

Lastly, Title III contains miscellaneous provisions. A severability provision specifies that if any part of GINA is held unconstitutional, the remainder of the Act will remain in effect.<sup>77</sup> Title III also amends the Fair Labor Standards Act by increasing the penalties for violating child labor laws and defining the term "serious injury."<sup>78</sup> Because Title III does not contain substantive provisions dealing with genetic-information discrimination, this Article focuses on Titles I and II.

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visited Mar. 2, 2010). If a claimant files a claim with a local or state Fair Employment Practice Agency ("FEPA") and federal antidiscrimination laws also apply, the FEPA will "dual-file" the claim with the EEOC; thus, the claimant does not need to file independently with both agencies. <http://www.eeoc.gov/employees/charge.cfm>. Federal employees have similar protections but must follow a different claims process. See EEOC, Overview of Federal Sector EEO Complaint Process, [http://www.eeoc.gov/federal/fed\\_employees/complaint\\_overview.cfm](http://www.eeoc.gov/federal/fed_employees/complaint_overview.cfm) (last visited Mar. 2, 2010).

74. See Genetic Information Nondiscrimination Act § 207. Congress plans to revisit this issue six years after the law's enactment. *Id.* § 208.

75. See *supra* notes 52–56 and accompanying text. Despite the firewall, there is some overlap. See EEOC Title II Proposed Rules, 79 Fed. Reg. 9056, 9065 (Mar. 2, 2009) (to be codified at 19 C.F.R. pt. 1635) (noting "the firewall does not immunize covered entities from liability for decisions and actions taken that violate Title II, including employment decisions based on health benefits, because such benefits are within the definition of compensation, terms, conditions, or privileges of employment").

76. Genetic Information Nondiscrimination Act § 209. GINA, therefore, creates a "floor" for the protection of genetic information without preempting state laws that offer more substantial protections. Section 209 also includes other rules of construction, including that GINA does not apply to the Armed Forces Repository of Specimen Samples for the Identification of Remains. *Id.*

77. *Id.* § 301.

78. *Id.* § 302.

## 2. Comparison of Titles I and II

GINA's substantive titles contain both notable similarities and relevant differences regarding the way in which they protect genetic information.

### *a. Definitions*

Both substantive titles contain similar—yet not identical—definitions of “genetic information” and “genetic test.” These definitions complement one another while accounting for different issues specific to either employment or health insurance.

#### i. Genetic Information

Both Title I and Title II define a person's “genetic information” as “(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 of such individual.”<sup>79</sup> Both definitions exclude any information related to sex or age<sup>80</sup> but include the genetic information of embryos and fetuses.<sup>81</sup>

While the definitions of genetic information in the two titles are similar, Title II contains an additional provision that differentiates between genetic-information discrimination and discrimination on the basis of a *manifested* genetic condition. This provision, Section 210, clarifies that with regard to Title II, “the use, acquisition, or disclosure of medical information that is not genetic information about a manifested disease, disorder, or pathological condition, even if such has or may have a genetic basis” cannot constitute the basis of a GINA employment discrimination claim.<sup>82</sup> Put

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79. *Id.* §§ 101(a)(2), 102(a)(2), 103(a)(2), 104(b), 201(4)(A)(i)–(iii). This definition appears to borrow heavily from an executive order issued by President Clinton, barring genetic-information discrimination against federal employees. *Supra* note 22.

80. Genetic Information Nondiscrimination Act §§ 101(a)(2), 102(a)(2), 103(a)(2), 104(b), 201(4)(C). Underwriting traditionally uses age, sex, and occupation, among other factors, to determine premiums.

81. The inclusion of fetal and embryonic genetic information was another area of compromise for GINA's supporters. See *Protecting Workers from Genetic Discrimination: Hearing Before the Subcomm. of Health, Employment, Labor and Pensions of the H. Comm. of Educ. and Labor*, 110th Cong. 25–26 (2007) (statement of Rep. Pete Hoekstra) (stating he was “very concerned” that GINA “[did] not protect an embryo, fetus or a child in the process of adoption from genetic discrimination”).

82. Genetic Information Nondiscrimination Act § 210.

differently, once genetic information manifests into an impairing condition, GINA no longer applies.<sup>83</sup>

## ii. Genetic Test

Unlike Title II, Title I does not contain a provision like Section 210 that explicitly states medical information about manifested conditions is not “genetic information.” However, Title I’s definition of “genetic test” limits its application to manifested disorders.<sup>84</sup> Both titles provide that “an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes” constitutes a genetic test.<sup>85</sup> Title I also exempts the following from its definition:

[An] analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes, or an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved.<sup>86</sup>

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83. Although the ADA protects employees against discrimination on the basis of disability—including those with genetic components—whether the discrimination is on the basis of genetic information or a manifested medical condition may not always be clear, thereby rendering the relationship between GINA and the ADA both ambiguous and complex. For example, an employer might fire a woman who suffers from cancer *and* who has a mutation on her BRCA1 gene. If the employer fires her merely on the basis of her mutated gene (genetic information)—perhaps without knowledge that she has developed cancer—GINA applies. Conversely, if the employer fires her specifically because of her cancer (manifested medical condition)—perhaps without knowledge of her genetic predisposition to cancer—the ADA applies. Things, of course, become far more complicated when employers are aware of both an employee’s genetic information and manifested medical conditions. In fact, anecdotes related to genetic-information discrimination blur this line. *See, e.g., supra* Part II.B.1.b; *see also* Jessica L. Roberts, *Antisubordination and the Genetic Information Nondiscrimination Act* (2010) (on file with author) (providing detailed description of GINA’s failure to cover manifested genetic conditions).

84. Once genetic information manifests into a related health condition, GINA no longer applies. At present, health insurers may limit benefits or increase premiums for people with manifested genetic disorders. *See Roberts, supra* note 83, at Part II. However, recently proposed health care reforms may bar health insurers from considering health status of any kind. *See* America’s Affordable Health Choices Act of 2009, H.R. 3200 (2009); Patient Protection and Affordable Care Act of 2009, H.R. 3590 (2009).

85. Genetic Information Nondiscrimination Act §§ 101(a)(2), 102(a)(2), 103(a)(2), 104(b), 201(7).

86. *Id.* § 101(d); 29 U.S.C. § 1191b-(d)(7)(B) (2006). In its proposed rules for interpreting Title II, the EEOC notes that:

Title II does not require this language of exclusion because Congress determined that these uses “are not applicable in the employment context.” However, . . . the Commission borrowed from Title I’s use of the term “manifest” in the definition of “genetic test” in formulating a definition of “manifested or manifestation.”

Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. 9056, 9059 (Mar. 2, 2009) (to be codified at 29 C.F.R. pt. 1365) (citing S. Rep. No. 110-48, at 28). Thus,

Thus, a test that detects a *manifested medical condition* is not a “genetic test” under Title I.

*b. Exceptions*

In drafting GINA, Congress included important exceptions intended both to benefit and protect health insurers and employers. For example, Title I includes a research exception that allows group health plans to request—but not require—a person to undergo genetic testing for research purposes, but only under certain conditions.<sup>87</sup> Title I also does not penalize insurers for incidentally acquiring genetic information.<sup>88</sup>

Similarly, Title II does not apply to the incidental acquisition of genetic information.<sup>89</sup> For instance, Congress sought to avoid the “water cooler problem.”<sup>90</sup> The “water cooler problem” occurs if an employer inadvertently obtains genetic information through casual conversation, such as when an employee mentions that her mother died of breast cancer.<sup>91</sup> Additionally, Title II does not cover information unwittingly acquired by purchasing commercially available documents that contain an employee’s family medical history, such as an obituary in a newspaper.<sup>92</sup>

Title II also includes exceptions for *intentionally* obtaining genetic information. An employer can lawfully acquire genetic information when offering certain genetic services such as employee

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while Title I and Title II exclude manifested medical conditions from GINA’s protection in different ways—Title I through its definition of “genetic test” and Title II through its definition of “genetic information”—the EEOC defines “manifest” with regard to its Title II proposed regulation in such a way that the term will remain consistent across both substantive Titles.

87. To request genetic testing under the research exception, a plan must ensure that compliance is voluntary and noncompliance has no effect on the insured’s status, none of the information will be used for underwriting purposes, and the Secretary of Health and Human Services is aware that research is being done. Genetic Information Nondiscrimination Act §§ 101(b), 102(a), 103(b), 104(b).

88. *Id.* §§ 101(b), 102(a), 103(b), 104(b).

89. *Id.* §§ 202(b), 203(b), 204(b), 205(b).

90. *See* S. Rep. No. 110-48, at 28 (2007).

91. Genetic Information Nondiscrimination Act §§ 202(b)(1), 203(b)(1), 204(b)(1), 205(b)(1). In its proposed rules, the EEOC extends this exception beyond the protection of family history to all inadvertently obtained genetic information. Regulations Under the Genetic Information Nondiscrimination Act of 2008, 79 Fed. Reg. 9056, 9061 (Mar. 2, 2009) (to be codified at 19 C.F.R. pt. 1635) (“Although the language of this exception in GINA specifically refers to family medical history, the Commission believes that it is consistent with Congress’s intent to extend the exception to any genetic information that an employer inadvertently acquires.”).

92. Genetic Information Nondiscrimination Act §§ 202(b)(4), 203(b)(4), 204(b)(4), 205(b)(4).

wellness programs,<sup>93</sup> when complying with the certification requirements of state and federal medical leave laws,<sup>94</sup> and when monitoring the effects of toxic substances on employees.<sup>95</sup> Another exemption relates to law enforcement forensic laboratories and applies only to employers and training programs.<sup>96</sup> Thus, Congress recognized the potentially beneficial aspects of acquiring genetic information and tailored both Title I and Title II to allow the limited acquisition and use of genetic information by health insurers and employers.

GINA is a carefully crafted law. Congress designed Title I and Title II to work in concert with one another and with the existing laws governing health insurance and employment discrimination. The next Part takes this analysis a step back by examining how the very nature of genetic-information discrimination differs from the discriminatory regimes targeted by previous statutes.

## II. RETROSPECTIVE VS. PREEMPTIVE ANTIDISCRIMINATION LEGISLATION

Traditionally, American antidiscrimination statutes have reacted to existing discrimination, looking to histories of exclusion or unequal treatment to justify their protections. GINA—while citing some examples of genetic-information discrimination—is far more oriented toward shaping the future than reflecting on the past. GINA is, therefore, perhaps the first American antidiscrimination statute specifically geared toward preempting a form of future discrimination before it becomes entrenched.

### *A. Retrospective Antidiscrimination Legislation*

Pre-GINA, four statutes prevented employers from discriminating against their workers: Title VII of the Civil Rights Act of 1964 (“Title VII”), the Age Discrimination in Employment Act (“ADEA”), the Rehabilitation Act of 1973, and Title I of the Americans

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93. *Id.* §§ 202(b)(2), 203(b)(2), 204(b)(2), 205(b)(2). To qualify for that exemption, the individual must give prior, knowing, voluntary, written authorization, only the individual and the authorized service provider must receive identifiable information pertaining to the results, and that information must not be provided to the employer, unless it is in unidentifiable, aggregate form.

94. *Id.* §§ 202(b)(3), 203(b)(3), 204(b)(3), 205(b)(3).

95. *Id.* §§ 202(b)(5), 203(b)(5), 204(b)(5), 205(b)(5). That exception requires the requesting entity to give written notice of the genetic monitoring, to receive prior, known, voluntary, written authorization from the employee to be monitored, to inform the monitored employee of the results, to comply with the relevant state and federal monitoring regulations, and only to receive the results in aggregate terms.

96. *Id.* §§ 202, 205.

with Disabilities Act (“ADA”).<sup>97</sup> Each of these laws addressed an existing discriminatory regime.

### 1. Title VII of the Civil Rights Act of 1964

On July 2, 1964, President Lyndon Johnson signed the Civil Rights Act of 1964. This landmark piece of legislation outlawed unequal treatment in education, public facilities, government, and employment.<sup>98</sup> Title VII of the Act prohibits employers from discriminating on the basis of race, color, national origin, religion, or sex.<sup>99</sup> Although the Court eventually interpreted the law to cover categories that had not traditionally experienced discrimination, such as men and whites,<sup>100</sup> Congress first passed Title VII primarily in reaction to existing discrimination against black Americans. When signing the law, President Johnson explained that “millions are being deprived of [the] blessings [of liberty]—not because of their own failures, but because of the color of their skin. . . . But it cannot continue.”<sup>101</sup> Even absent explicit congressional findings,<sup>102</sup> the

97. Because GINA deals specifically with the workplace, this Section focuses on employment discrimination laws. Other types of antidiscrimination legislation, like Section 5 of the Voting Rights Act of 1965 (VRA), justify protection based on existing discrimination. 42 U.S.C. § 1973(b) (2006):

[A violation of the VRA has occurred] if, based on the totality of circumstances, it is shown that the political processes leading to nomination or election in the State or political subdivision are not equally open to participation by members of a class of citizens protected by subsection (a) in that its members have less opportunity than other members of the electorate to participate in the political process and to elect representatives of their choice.

98. Civil Rights Act of 1964, 42 U.S.C. §§ 1971, 1975a–d, 2000 (2006).

99. Section 703(a) of Title VII provides:

It shall be an unlawful employment practice for an employer—

(1) to fail or refuse to hire or to discharge any individual, or otherwise to discriminate against any individual with respect to his compensations, terms, conditions, or privileges of employment, because of such individual’s race, color, religion, sex, or national origin; or

(2) to limit, segregate, or classify his employees or applicants for employment in any way which would deprive or tend to deprive any individual of employment opportunities, or otherwise adversely affect his status as an employee, because of such individual’s race, color, religion, sex, or national origin.

42 U.S.C. § 2000e.

100. *See, e.g.,* *Yeary v. Goodwill Indus.-Knoxville, Inc.*, 107 F.3d 443, 445 (6th Cir. 1997) (holding that “Title VII . . . applies equally to men and women”); *McDonald v. Santa Fe Trail Transp. Co.*, 427 U.S. 273, 282 (1976) (holding that Title VII applies equally “to members of all races”).

101. WHALEN & B. WHALEN, *THE LONGEST DEBATE: A LEGISLATIVE HISTORY OF THE 1964 CIVIL RIGHTS ACT* 227–28 (1985). Thus, although the statute includes other groups, advocates

Supreme Court has continually interpreted Title VII as reacting to past discrimination against all the named categories.<sup>103</sup> Thus, Title

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intended Title VII to integrate Black Americans economically by improving their access to employment opportunities. See Sandi Farrell, *Toward Getting Beyond the Blame Game: A Critique of the Ideology of Voluntarism in Title VII Jurisprudence*, 92 KY. L.J. 483, 490 (2003–2004) (“It seems beyond dispute that job segregation on the basis of race and sex was the principal phenomenon that Title VII was intended to ameliorate.”); see also SAMUEL ESTREICHER & MICHAEL C. HARPER, *EMPLOYMENT DISCRIMINATION & EMPLOYMENT LAW* 53 (3d ed. 2008) (“Passed over considerable opposition by representatives from the Southern states, Title VII extended antidiscrimination commands to private employment, and sought to promote the economic integration of blacks into mainstream American society.”).

102. Unlike with other antidiscrimination statutes, Congress provided no official findings when enacting the Civil Rights Act. However, the Act has an extensive legislative history. See ESTREICHER & HARPER, *supra* note 101, at 227–28 (providing an overview of the Act’s legislative history).

103. The Court described Title VII as “a complex legislative design directed at a historic evil of national proportions” in *Albemarle Paper Co. v. Moody*, 422 U.S. 405, 418 (1975). Similarly, in *Griggs v. Duke Power Co.*, the Court again indicated that Congress intended Title VII to remedy existing discrimination: “[t]he objective of Congress in the enactment of Title VII is plain from the language of the statute. It was to achieve equality of employment opportunities and remove barriers that have operated in the past to favor an identifiable group of white employees over other employees.” 401 U.S. 424, 429–30 (1971). The Court expressed a similar sentiment a year later in its opinion in *United Steelworkers v. Weber*, stating that “Congress’ primary concern in enacting the prohibition against racial discrimination in Title VII of the Civil Rights Act of 1964 was with ‘the plight of the Negro in our economy.’” 443 U.S. 193, 202 (1972) (quoting 110 Cong. Rec. 6548 (1964) (remarks of Sen. Humphrey)). The Court went on to explain:

Before 1964, blacks were largely relegated to “unskilled and semi-skilled jobs.” Because of automation the number of such jobs was rapidly decreasing. As a consequence, “the relative position of the Negro worker [was] steadily worsening. In 1947 the nonwhite unemployment rate was only 64 percent higher than the white rate; in 1962 it was 124 percent higher.” Congress considered this a serious social problem. As Senator Clark told the Senate: “The rate of Negro unemployment has gone up consistently as compared with white unemployment for the past 15 years. This is a social malaise and a social situation which we should not tolerate. That is one of the principal reasons why the bill should pass.”

*Id.* (internal citations omitted).

Because Title VII’s legislative history focuses primarily on race (and color), there is very little discussion of the other categories. See EQUAL EMPLOYMENT OPPORTUNITY COMM’N, *LEGISLATIVE HISTORY OF TITLES VII & XI OF CIVIL RIGHTS ACT OF 1964*, at 3–11 (1968). However, the Supreme Court had already treated national origin discrimination with the same level of equal protection scrutiny as race, see *Korematsu v. United States*, 323 U.S. 214, 216–17 (1944) (treating the exclusion of Japanese Americans as racial exclusion), indicating that discrimination on the basis of national origin was already occurring. Similarly, the First Amendment protected religious groups against discrimination. U.S. CONST. amend. I; see also *Everson v. Bd. of Educ.*, 330 U.S. 1, 8–15 (1947) (reviewing the history of religious discrimination in the United States to provide background for the First Amendment’s protection of religion). The Supreme Court noted:

[t]he meaning and scope of the First Amendment, preventing establishment of religion or prohibiting the free exercise thereof, in the light of its history and the evils it was designed forever to suppress, have been several times elaborated by the decisions of this Court prior to the application of the First Amendment to the states by the Fourteenth.



VII is a retrospective statute, looking to past discrimination to justify protection in the present and in the future.

## 2. Age Discrimination in Employment Act

The ADEA, which Congress passed in 1967,<sup>104</sup> is also backward-gazing. The law prohibits employment discrimination against individuals forty years of age and over.<sup>105</sup> Much like GINA, it is a hybrid: it combines substantive law drawn from Title VII with remedies from the Fair Labor Standards Act of 1938.<sup>106</sup> In passing the ADEA, Congress explicitly referenced older workers' inability to retain or regain employment and the resulting unemployment of older Americans.<sup>107</sup> Thus, as with Title VII, Congress sought to protect a particular group—people over forty—based on discrimination that group members had faced in the past.<sup>108</sup>

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*Everson*, 330 U.S. at 14–15. Although sex discrimination was not yet recognized as constitutionally prohibited in 1964, following the 1972 amendments, courts interpreted Title VII as an effort to remedy discrimination against women, who had suffered tangible disadvantage in the workplace by virtue of their sex. *Holloway v. Arthur Andersen & Co.*, 566 F.2d 659, 664 (9th Cir. 1977) (“[T]he clear intent of the 1972 legislation was to remedy the economic deprivation of women as a class. The cases interpreting Title VII sex discrimination provisions agree that they were intended to place women on an equal footing with men.”).

104. Age Discrimination in Employment Act of 1967 (ADEA), 29 U.S.C. § 621 [*hereinafter* ADEA]; *see also* ESTREICHER & HARPER, *supra* note 101, at 428 (noting that while Congress failed to enact age discrimination statute in 1964 it remedied this failure in 1967 with the enactment of ADEA).

105. In *General Dynamics Land Systems, Inc. v. Cline*, 540 U.S. 581 (2004), plaintiffs argued that in addition to prohibiting discrimination against the old in favor of the young, the ADEA prohibits discriminatory preferences against the young in favor of the old. The Supreme Court held that it does not.

106. ESTREICHER & HARPER, *supra* note 101, at 428; *see also* JOEL WM. FRIEDMAN, *THE LAW OF EMPLOYMENT DISCRIMINATION* 810 (6th ed. 2007):

The substantive portions of the ADEA, including the prohibitions against retaliation and discriminatory advertising are . . . virtually identical to the antidiscrimination provisions of Title VII. The major difference, of course, is that the ADEA only prohibits discrimination on the basis of age and only as to persons 40 years of age or older.

107. Congress found that older workers were at a disadvantage with regard to their ability “to retain employment, and especially to regain employment when displaced from jobs.” ADEA § 621(a)(1). Congress noted that age limits—as well as other employment practices—may contribute to this disadvantage. *Id.* § 621(a)(2). It explained:

[T]he incidence of unemployment, especially long-term unemployment with resultant deterioration of skill, morale, and employer acceptability is, relative to the younger ages, high among older workers; their numbers are great and growing; and their employment problems grave.

*Id.* § 621(a)(3).

108. Unlike that against women or racial minorities, the discrimination against older workers is most likely not as animus-based. ESTREICHER & HARPER, *supra* note 101, at 425 (“The

### 3. The Rehabilitation Act of 1973 and the Americans with Disabilities Act

The Rehabilitation Act and the Americans with Disabilities Act are likewise retrospective. Passed six years after the ADEA, the Rehabilitation Act of 1973 prohibits discrimination on the basis of disability in federal programs and in federal employment, including federal contract work.<sup>109</sup> The statute includes a number of congressional findings, justifying its protection based on discrimination faced by people with disabilities.<sup>110</sup>

Almost two decades later, President George H. W. Bush signed the ADA into law. The statute, divided into five titles, addresses disability discrimination in employment, government services, public and commercial accommodations, and telecommunications.<sup>111</sup> Specifically, Title I forbids employers from discriminating against a qualified individual on the basis of a disability in hiring, promotion, training, and other job-related decisions.<sup>112</sup> Title I of the ADA seeks to provide disabled people with equal employment opportunities and economic independence.

Congress made several findings detailing the discrimination and exclusion endured by people with disabilities.<sup>113</sup> As with race in Title VII, the justification for outlawing discrimination stems from two sources: society's exclusion of an entire class of qualified people from

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role of employee and customer prejudice in reinforcing the use of age stereotypes by employers is probably less significant than for race and sex stereotyping.”).

109. Rehabilitation Act of 1973, 29 U.S.C. §§ 701–796 (2006).

110. Congress found that “millions of Americans have one or more physical or mental disabilities and the number of Americans with such disabilities is increasing” and that “individuals with disabilities constitute one of the most disadvantaged groups in society.” *Id.* § 701(a)(1)–(2). Additionally, it noted that “individuals with disabilities continually encounter various forms of discrimination in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and public services . . . .” *Id.* § 701(a)(5). The Rehabilitation Act was, therefore, looking to evidence of existing discrimination to justify antidiscrimination protection for people with disabilities.

111. Title V of the ADA includes miscellaneous technical provisions.

112. Americans with Disabilities Act of 1990, Title I, 42 U.S.C. § 12112(a) (2006) (“No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment.”).

113. For instance, Congress noted that “historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.” *Id.* § 12101(a)(2). Congress further explained that census and poll data indicated that “people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally.” *Id.* § 12101(a)(6).

employment based on unfair stereotypes, and Congress's desire to put an end to that cycle of discrimination.<sup>114</sup> The amendments to the ADA echoed this sentiment in their findings, stating that "in enacting the ADA, Congress recognized that . . . people with physical or mental disabilities are frequently precluded from [fully participating in all aspects of society] because of prejudice, antiquated attitudes, or the failure to remove societal and institutional barriers."<sup>115</sup> Thus, the disadvantage experienced by people with disabilities has been a crucial element of Congress's decision to protect them against discrimination, even as recently as 2008.

Judging from Title VII, the ADEA, the Rehabilitation Act, and the ADA, antidiscrimination traditionally tends to be retrospective—looking back at the historical treatment of disadvantaged groups to justify their protection. GINA, however, stands apart as perhaps the first preemptive antidiscrimination statute.

### *B. Preemptive Antidiscrimination Legislation*

Unlike the preceding statutes—which respond to existing inequities—little evidence indicates that genetic-information discrimination is currently taking place on a large scale.

Genetic-information discrimination has arguably been happening in some form or another for over a hundred years. Perhaps the most notorious example of this phenomenon is eugenics, the use of early genetic science to advocate eliminating particular socially undesirable traits.<sup>116</sup> GINA, however, envisions a different sort of

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114. See Colin S. Diver & Jane Manslow-Cohen, *Point/Counterpoint: Genophobia: What is Wrong with Genetic Discrimination*, 149 U. PA. L. REV. 1439, 1478–79 (2001):

The moral justification for prohibiting disability discrimination is comparable to that used to justify prohibitions on racial or gender discrimination. Our society has, due to irrational prejudice and fear, excluded a class of persons with certain readily identifiable conditions, fairly described as 'disabilities,' from activities, such as employment, which they are otherwise qualified to perform. Thus, an employer who excludes a person from an otherwise suitable job solely because of her disability actively perpetuates that history of oppression and subordination. In that sense, the employer implicates herself sufficiently in the applicant's misfortune to become morally responsible for its perpetuation.

115. ADA Amendments Act of 2008, Pub. L. No. 110-325, 122 Stat. 3557, § 2(a)(2).

116. Among the strategies used by eugenicists was forced sterilization. JACQUELINE VAUGHN SWITZER, *DISABLED RIGHTS: AMERICAN DISABILITY POLICY AND THE FIGHT FOR EQUALITY* 37 (2003). The case, *Buck v. Bell*, 274 U.S. 200 (1927), is a notorious example. In upholding a Virginia statute allowing for the involuntary sterilization of the "feeble-minded," the Supreme Court reasoned that because "heredity plays an important part in the transmission of insanity, imbecility, etc.," it is, therefore, preferable to "prevent those who are manifestly unfit from continuing their kind." *Id.* at 205, 206, 207.

coverage, primarily seeking to protect genetic information acquired through modern genetic testing.<sup>117</sup> Moreover, GINA limits its protection to health insurance and employment.<sup>118</sup> Thus, while genetic-information discrimination may have occurred in some capacity in the past, few cases have dealt with the variety of genetic-information discrimination that GINA specifically targets.

GINA's detractors saw this lack of history as a fatal flaw in the legislation. GINA's supporters, however, turned this criticism on its head by urging Congress to do something it had never done—attempt to stop discrimination before it takes hold. GINA, therefore, targets a form of discrimination not yet happening extensively.<sup>119</sup>

### 1. Evidence of a History of Genetic-Information Discrimination

Because antidiscrimination protection often draws from past discriminatory treatment, GINA's proponents attempted to demonstrate a longstanding history of genetic-information discrimination.<sup>120</sup> For example, in its findings, Congress connected

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117. As mentioned, GINA does consider family histories to be genetic information, yet the law focuses a great deal on the role of genetic testing. See, e.g., Perry W. Payne, Jr., *Genetic Information Nondiscrimination Act of 2008: The Federal Answer for Genetic Discrimination*, 5 J. HEALTH & BIOMED. L. 33, 60 (2009) (explaining that GINA "concerns a genetic testing market that remains quite limited other than perhaps cancer screening and genetic testing for newborns"); Michael S. Blackwell, Comment, *Insurance, Employment, and the Genetic Information Nondiscrimination Act of 2008*, 55 LOY. L. REV. 125, 139 (2009) (observing that "[t]he definition of 'genetic information' is based primarily on the definition of 'genetic test'").

118. There is, perhaps, a new eugenics on the rise; however GINA would do little to protect against it. See, e.g., Kathleen Kingsbury, *Which Kids Join Gangs? A Genetic Explanation*, TIME, June 10, 2009, available at <http://www.time.com/time/health/article/0,8599,1903703,00.html> (linking genetics to gang membership).

119. *But see* Statement of Paul Steven Miller, *supra* note 16 (citing the same survey for the statement that "genetic service providers and primary care physicians reported knowing of 582 people who were refused employment or insurance based on their genetic predisposition"); Julian Borger, *Health Warning as DNA Screening Takes Hold, Americans Find it Can Leave Them Unemployed and Uninsured: Who's Testing Our Genes—and Why?*, GUARDIAN (London), Sept. 19, 2000, at 15 (noting that a survey revealed over five hundred cases of genetic-information discrimination in employment). Despite the numbers, however, that survey does not indicate pervasive genetic-information discrimination, but merely that genetic-information discrimination is happening at some level. See Statement of Paul Steven Miller, *supra* note 16 ("The study's authors note that although this number is modest in relation to the total number of patients seen by the surveyed professionals, genetic discrimination does in fact exist.").

120. See, e.g., SEC'Y'S ADVISORY COMM. ON GENETICS, HEALTH, & SOC'Y, U.S. DEP'T OF HEALTH & HUMAN SERVS PUBLIC PERSPECTIVES ON GENETIC DISCRIMINATION: SEC'Y'S ADVISORY COMM. ON GENETICS, HEALTH, & SOC'Y 21 (2004), available at [http://oba.od.nih.gov/oba/sacghs/reports/Public\\_Perspectives\\_GenDiscrim.pdf](http://oba.od.nih.gov/oba/sacghs/reports/Public_Perspectives_GenDiscrim.pdf) [hereinafter PUBLIC PERSPECTIVES] (statement of Caroline Hinestrosa) ("As we clearly can see from the witnesses here today, genetic discrimination is a real and growing problem that needs an immediate solution, not one that should wait until we have further cases of women and men who have experience this type of discrimination that is so detrimental to the ability to seek quality health care.").

genetic-information discrimination with forced sterilization,<sup>121</sup> racially targeted screenings for sickle cell anemia,<sup>122</sup> and a 1998 Ninth Circuit privacy case dealing with pre-employment genetic testing.<sup>123</sup> Yet while both legal and anecdotal evidence indicates that some genetic-information discrimination was indeed occurring, it was on a rather limited basis.

*a. Legal Evidence of Genetic-Information Discrimination*

Three federal cases addressed genetic-information discrimination pre-GINA. As mentioned, Congress cited one of these

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121. See Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881, § 2(2) (2008):

The early science of genetics became the basis of State laws that provided for the sterilization of persons having presumed genetic “defects” such as mental retardation, mental disease, epilepsy, blindness, and hearing loss, among other conditions. The first sterilization law was enacted in the State of Indiana in 1907. By 1981, a majority of States adopted sterilization laws to “correct” apparent genetic traits or tendencies. Many of these State laws have since been repealed, and many have been modified to include essential constitutional requirements of due process and equal protection. However, the current explosion in the science of genetics, and the history of sterilization laws by the States based on early genetic science, compels Congressional action in this area.

122. See *id.* § 2(3):

Although genes are facially neutral markers, many genetic conditions and disorders are associated with particular racial and ethnic groups and gender. Because some genetic traits are most prevalent in particular groups, members of a particular group may be stigmatized or discriminated against as a result of that genetic information. This form of discrimination was evident in the 1970s, which saw the advent of programs to screen and identify carriers of sickle cell anemia, a disease which afflicts African-Americans. Once again, State legislatures began to enact discriminatory laws in the area, and in the early 1970s began mandating genetic screening of all African Americans for sickle cell anemia, leading to discrimination and unnecessary fear. To alleviate some of this stigma, Congress in 1972 passed the National Sickle Cell Anemia Control Act, which withholds Federal funding from States unless sickle cell testing is voluntary.

123. See *id.* § 2(4) (“Congress has been informed of examples of genetic discrimination in the workplace. These include the use of pre-employment genetic screening at Lawrence Berkeley Laboratory, which led to a court decision in favor of the employees in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1269 (9th Cir. 1998). Congress clearly has a compelling public interest in relieving the fear of discrimination and in prohibiting its actual practice in employment and health insurance.”). Similarly, Dean Karen Rothenberg linked genetic-information discrimination to Eugenics, genetic inferiority, and the Holocaust. See *Protecting Workers From Genetic Discrimination: Hearing Before the Subcomm. on Health, Employment, Labor, and Pensions of the H. Comm. on Educ. and Labor*, 110th Cong., 131–32 (2007) (statement of Karen Rothenberg, University of Maryland School of Law) [*hereinafter* Statement of Karen Rothenberg] (stating that “eugenics was the scientific justification for killing millions during the holocaust”).

cases, *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, in GINA's findings.<sup>124</sup> According to the plaintiffs, Lawrence Berkeley Laboratory had a practice of testing its prospective employees' blood and urine—without their knowledge or consent—for a series of “intimate medical conditions,” including sickle cell, syphilis, and pregnancy.<sup>125</sup> As a result, employees sued the laboratory, its director, a group of medical doctors employed by the lab, and members of California state government for violating Title VII, the ADA, and their state and federal rights to privacy.<sup>126</sup> Regarding Title VII, the plaintiffs alleged that the lab and the Regents of the University of California violated the law by targeting black employees with sickle cell testing and women with pregnancy screening.<sup>127</sup> With respect to the ADA, the plaintiffs argued that the defendants inappropriately engaged in unnecessary medical testing.<sup>128</sup>

The district court dismissed all of the claims as time-barred, finding that the statute of limitations began running at the time the plaintiffs unwittingly took the test.<sup>129</sup> When the plaintiffs appealed to the Ninth Circuit, that court held that the ADA claims failed on the merits and therefore affirmed with respect to those claims.<sup>130</sup> However, it reversed and remanded on the Title VII and constitutional issues.<sup>131</sup> The following year, the parties settled for \$2.2 million.<sup>132</sup> The Ninth Circuit's holding suggests that Title VII might provide some protection against employers' testing for genetic traits when those traits implicate protected groups.

Another oft-cited example of genetic-information discrimination involved Burlington Northern Santa Fe Corporation. After employees began complaining that they developed carpal tunnel syndrome from their jobs, Burlington Northern tested them for a genetic predisposition to the disorder without their knowledge.<sup>133</sup> The EEOC sued Burlington Northern under the ADA.<sup>134</sup> Although the

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124. *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260 (9th Cir. 1998); see *supra* note 123 and accompanying text.

125. *Norman-Bloodsaw*, 135 F.3d at 1264.

126. *Id.*

127. *Id.* at 1265–66.

128. *Id.* at 1265.

129. *Id.* at 1266.

130. *Id.* at 1275.

131. *Id.*

132. Lisa Girion, *Nurse Derails Genetic Testing: Wife of Railroad Worker Sparks Probe That May Have Wide Implications*, L.A. TIMES, Feb. 25, 2001, at W1.

133. *Id.*

134. T. Shawn Taylor, *Railroad Settles Genetic-Test Suit: U.S. Contended Exams Violated Disabilities Act*, CHI. TRIB., May 9, 2002, at N3.

company maintained it did not violate the ADA, Burlington Northern settled with the EEOC (coincidentally) for \$2.2 million.<sup>135</sup>

A final example involves Terri Sergeant, a manager at an insurance company, who lost her job after being diagnosed with alpha-1 antitrypsin deficiency, a genetic condition that manifests as a progressive lung disorder.<sup>136</sup> Being newly unemployed and with a preexisting medical condition, Sergeant soon lost her disability, health, and life insurance.<sup>137</sup> She then filed an ADA claim with the EEOC, which after investigation supported Sergeant's allegation and issued her a permission-to-sue letter.<sup>138</sup>

These three cases constitute what may be the entirety of documented federal genetic-information discrimination claims prior to GINA.<sup>139</sup> Yet, even if the above cases demonstrate a history of genetic-information discrimination, they arguably imply that separate genetic antidiscrimination legislation is unnecessary, as claimants potentially could have obtained relief under Title VII or the ADA.<sup>140</sup>

#### *b. Anecdotal Evidence of Genetic-Information Discrimination*

In addition to the three cases above, GINA's proponents also cited several anecdotal examples of genetic-information discrimination. In 2004, the Secretary's Advisory Commission on Genetics, Health, and Society ("SACGHS") held a forum on public perspectives on genetic-information discrimination. Several people shared their stories when they testified before SACGHS. Heidi Williams spoke about how an insurer initially denied her children health insurance because they were carriers of the gene for alpha-1

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135. *Id.*

136. *Discrimination in Workplace Now Includes Genetics*, BUFFALO NEWS, July 30, 2001, at B1.

137. JONES & SARATA, *supra* note 5, at 20.

138. *Id.*

139. There is arguably a fourth genetic information case. In *EEOC v. Woodbridge Corp.*, 263 F.3d 812, 813 (8th Cir. 2001), the EEOC sued on behalf of nineteen job applicants who had received offers but were ultimately denied employment based on the results of a neurometric test that screened for a proclivity to develop carpal tunnel syndrome. Although the test did not analyze the genetic material of the applicants, it screened them for a *predisposition*—which could have been genetic—to develop a particular medical condition. The district court granted summary judgment and the Eighth Circuit affirmed, holding that Woodbridge did not regard the prospective employees as generally disabled, just precluded from performing one particular, specialized job. *Id.* at 816.

140. In reference to the *Burlington Northern* case, Burton J. Fishman stated that the case "demonstrates that current laws were able to resolve the matter completely." Statement of Burton J. Fishman, *supra* note 45.

antitrypsin deficiency.<sup>141</sup> Phaedra Malatek discussed her family history of hemochromatosis and how she did not seek genetic testing for her two young sons for fear of discrimination by insurers.<sup>142</sup> Rebecca Fisher told the Committee about hiding her BRCA1 (a gene associated with breast cancer) mutation from healthcare providers.<sup>143</sup> Tonia Phillips explained that when she tested positive for BRCA1 and underwent a preventive hysterectomy and a preventive mastectomy, her boss confronted her about insurance costs and offered to pay her to switch to her husband's plan.<sup>144</sup> Paula Funk recanted how—because of her strong family history of breast cancer—she paid for her own genetic test and, after testing BRCA1 positive, was still waiting for approval from her insurance company for her preventive mastectomy.<sup>145</sup> Caroline Hinestrosa, a breast cancer survivor and executive vice president of National Breast Cancer Coalition, explained to SACGHS that she did not undergo genetic testing out of concern that the results could negatively impact her daughter.<sup>146</sup> Lastly, Phil Hardt, diagnosed with both hemophilia B and Huntington's Disease ("HD"), relayed how he hid his hemophilia from his boss, was denied credit insurance and long term care insurance because of his HD, had a daughter who was told that she had to test negatively for HD to get life insurance, and regretted that his grandson could not obtain health insurance because of his inherited hemophilia.<sup>147</sup> He also told the Committee that his two children paid out of pocket for HD tests and that he had helped set up anonymous testing for HD.<sup>148</sup>

In addition to the testimony, SACGHS received written statements, e-mails, and letters documenting stories of genetic-information discrimination. However, the voluminous number of responses is somewhat misleading. Not all the examples sent to the SACGHS were the sort of discrimination envisioned by GINA. For example, in one email, a mother whose son has ectodermaldysplasia, a disease that may manifest as missing or irregular teeth, wrote about how their dental insurance would not cover his dentures.<sup>149</sup> She also

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141. PUBLIC PERSPECTIVES, *supra* note 120, at 2–4 (statement of Heidi Williams).

142. *Id.* at 5–8 (statement of Phaedra Malatek).

143. *Id.* at 9–13 (statement of Rebecca Fisher).

144. *Id.* at 14–15 (statement of Tonia Phillips).

145. *Id.* at 16–19 (statement of Paula Funk).

146. *Id.* at 20–22 (statement of Carolina Hinestrosa).

147. *Id.* at 23–25 (statement of Phil Hardt).

148. *Id.*

149. E-mail from Pam Kennedy to Amanda K. Sarata (Aug. 20, 2004), in PUBLIC PERSPECTIVES, *supra* note 120, at 47.



mentioned that because people with ectodermal dysplasia may not have sweat glands, they require air conditioning in school or at work.<sup>150</sup> Her story is sympathetic to be sure, but her situation is an example of discrimination on the basis of genetically based disability rather than discrimination on the basis of genetic information.<sup>151</sup> Thus, while it might appear at first blush that genetic-information discrimination occurs with some frequency, many of the stories collected by SACGHS are not the type of conduct GINA covers.

## 2. Evidence Against a History of Genetic-Information Discrimination

While many of GINA's proponents maintained that genetic-information discrimination has posed a historical threat, other sources indicated that these cases may be isolated incidents. For example, a GINA-related congressional report stated that "[l]egal cases of genetic discrimination have been few."<sup>152</sup> Despite numerous state law provisions,<sup>153</sup> at the time of GINA's passing, no one had brought a genetic-information employment discrimination case under those statutes before any federal or state court, and the EEOC had settled only one lawsuit—the *Burlington Northern* case—related to genetic-information discrimination.<sup>154</sup> In fact, some have argued that the very notoriety of that case indicates it is more the exception than the rule for employers.<sup>155</sup> Others have claimed that evidence of genetic-

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150. *Id.*

151. Similarly, while the Council for Responsible Genetics maintains it documented "as many as five hundred cases" of genetic-information discrimination, CouncilforResponsibleGenetics.org, Genetic Testing, Privacy, and Discrimination, <http://www.councilforresponsiblegenetics.org/Projects/PastProject.aspx?projectId=1> (last visited Jan. 24, 2010), its position paper on genetic discrimination features examples not considered genetic-information discrimination under GINA, including a diagnosis of Fragile X syndrome (an inherited developmental impairment) and a woman's failure to be tested for BRCA-1 out of fear that a positive result could affect her at work. Council for Responsible Genetics, *Genetic Discrimination*, available at <http://www.councilforresponsiblegenetics.org/pageDocuments/2RSW5M2HJ2.pdf> (last visited Jan. 23, 2010).

152. NANCY LEE JONES & ALLISON M. SMITH, CONG. RESEARCH SERV. REPORT FOR CONG., NO. RL30006, GENETIC INFORMATION: LEGAL ISSUES RELATING TO DISCRIMINATION AND PRIVACY 3 (updated Mar. 11, 2005); see also Gaia Bernstein, *The Paradoxes of Technological Diffusion: Genetic Discrimination and Internet Privacy*, 39 CONN. L. REV. 241, 245 (2006) (noting that "[g]enetic discrimination is rare and apparently on the decline").

153. See *supra* note 28 (discussing history of state-enacted protections against genetic-information discrimination).

154. National Human Genome Research Institute, The Role of NHGRI in the Legislative Process, <http://www.genome.gov/12513976> (last reviewed May 11, 2009) (discussing an EEOC suit against Burlington Northern Santa Fe Railroad).

155. See Statement of Burton J. Fishman, *supra* note 45 (discussing opposition to proposed federal genetic antidiscrimination provisions); see also Bernstein, *supra* note 152, at 258–59

information discrimination in insurance is equally scant.<sup>156</sup> Even within the scientific community, “[f]ew claims of [genetic-information] discrimination have in fact been systematically investigated, verified, or documented.”<sup>157</sup>

Not surprisingly, opponents used the lack of historical discrimination to argue GINA was unnecessary, disparaging the law as “a remedy in search of a problem.”<sup>158</sup> In particular, they noted that the lack of a history set GINA apart from the antidiscrimination statutes preceding it:

[I]n the more than thirty states which have laws prohibiting genetic discrimination, there have been no reported cases, even though several statutes were enacted decades ago. Thus, there is no empirical evidence of genetic discrimination in employment, unlike the mountains of evidence of discriminatory conduct which preceded the passage

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(noting that empirical evidence of genetic-information discrimination by employers indicates it is rare and on the decline).

156. See Louis P. Garrison et al., *A Review of Public Policy Issues in Promoting the Development and Commercialization of Pharmacogenomic Applications: Challenges and Implications*, 40 *DRUG METABOLISM REVS.* 377, 395 (2008) (stating that at the time of GINA's passing there had been “virtually no evidence of genetic information discrimination in the insurance market”); see also Bernstein, *supra* note 152, at 259–60 (discussing survey research finding that insurers rarely discriminate on the basis of genetic information and that “little or no genetic discrimination by health insurers is taking place”).

157. Diver & Manslow-Cohen, *supra* note 114, at 1463.

158. Statement of Burton J. Fishman, *supra* note 45; see also Maria Ghazal, Health Policy Director, American Benefits Council, *quoted in* Mark A. Hofmann, *Genetic Bias Legislation Not Needed, Some Say*, *BUS. INS.* 4 (Oct. 20, 2003) (referring to the 2003 version of GINA as “a solution in search of a problem”). The lack of existing genetic discrimination is, therefore, a common criticism. ERIN. D. WILLIAMS, AMANDA K. SARATA & C. STEPHEN REDHEAD, CONGRESSIONAL RESEARCH SERVICE REPORT, NO. RL33903, *GENETIC DISCRIMINATION: OVERVIEW OF THE ISSUE AND PROPOSED LEGISLATION* (updated Mar. 7, 2007) (“Some employers question whether legislation is necessary because there are few documented cases of discrimination based on genetic information, and there is no evidence that employers would use the information if they had it. In addition, employers argue that existing law provides adequate protection against genetic discrimination in employment.”). One counterargument offered by GINA's supporters was that genetic-information discrimination was indeed taking place, but for one reason or another just could not be proven. Statement of Karen Rothenberg, *supra* note 123 (arguing that in addition to insurers' and employers' current failure to use genetic information, two possible reasons for the lack of evidence of discrimination are (1) that victims of discrimination simply do not know on what basis insurers and employers are making their decisions and (2) that cases may be settled or otherwise go unreported); see also Karen Rothenberg & Sharon Terry, *Before It's Too Late: Addressing Fear of Genetic Information*, 297 *SCI.* 196, July 12, 2002, at 196–97 (arguing the same). I do not spend much time on this line of reasoning because it does not effectively advocate the passing of a separate and distinct genetic antidiscrimination statute. If the reason for so few lawsuits is (1), GINA will make no difference because claimants cannot combat discrimination if they do not know they are victims in the first place. If an individual does not know she has suffered genetic-information discrimination, she certainly will not be able prove it in court. With regard to (2), settling cases pre-GINA implies that genetic discrimination victims have potentially viable claims under preexisting laws.

of other nondiscrimination laws, such as Title VII of the Civil Rights Act, the Age Discrimination in Employment Act, and the Americans with Disabilities Act.<sup>159</sup>

Thus, opponents viewed the absence of documented discrimination as a major strike against GINA. In fact, some even maintained that science has not yet evolved to a point at which we know enough about genetic information to use it to discriminate.<sup>160</sup> GINA's opponents, however, were not alone in discussing the lack of genetic-information discrimination.

GINA's supporters used the absence of significant genetic-information discrimination as a selling point. For example, Representative Louise Slaughter pointed out the absurdity of waiting for more discrimination to occur before outlawing it.<sup>161</sup> Senator Olympia Snowe asserted that GINA's supporters were "all taking a stand that, as we look to the future, genetic discrimination will not be allowed to flourish, to take root."<sup>162</sup> Senator James Jeffords similarly championed the preemptive law, urging Congress to "take that rare opportunity to be ahead of the curve and enact legislation to preempt discriminatory practices and prevent them from ever happening."<sup>163</sup> Whereas GINA's opponents viewed the lack of genetic-information discrimination as a weakness, its advocates saw it as an exciting opportunity to preempt a new form of discrimination.

Thus, members on both sides of the GINA debate agreed that genetic-information discrimination was not yet occurring widely.

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159. Statement of Burton J. Fishman, *supra* note 45. On a similar note, according to the U.S. Chamber of Commerce's Director of Labor Policy, Michael Eastman, "[o]ther anti-discrimination laws, such as those of race or disabilities, were enacted after years of abuse—and that hasn't happened with genetic testing." Marni Pyke, *Can 'Positive' be a Negative on Your Job and Insurance?*, CHI. DAILY HERALD, Oct. 20, 2005, at 1.

160. Some scholars have argued that genetic-information discrimination is not occurring significantly at present because it *cannot*. We currently lack the scientific know-how to be able to discriminate on the basis of genetic information because we do not yet understand enough about the relationship between genetics and disease. Diver & Manslow-Cohen, *supra* note 114, at 1476–77 ("There is no corresponding history of discrimination against the 'genetically disadvantaged.' Indeed, there cannot be. The science that could permit the construction of such a class is still in its infancy."); cf. 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) (arguing for the protection of genetic information but noting the "limited data gauging the extent of actual discrimination due to the fairly recent development of genetic screening and the inherent problem that exists in documenting such discrimination").

161. Letter from Rep. Louise Slaughter to the Members of the Sec'y Comm. on Genetics, Health, & Soc'y (Sept 3, 2004), in PUBLIC PERSPECTIVES, *supra* note 120, at 56 (2004) ("Congress should not wait to act until hundreds or thousands of people have experienced genetic discrimination.").

162. Ricardo Alonso-Zaldivar, *Senate Backs Privacy for Genetic Data*, L.A. TIMES, Apr. 25, 2008, at A1 (quoting Sen. Olympia Snowe).

163. Press Release, Office of Sen. James M. Jeffords, Senate Passes Sen. Jeffords' Genetic Non-Discrimination Bill (Feb. 17, 2005).

Unlike the traditional retrospective antidiscrimination statutes, GINA targets the *potential* for genetic-information discrimination. GINA is therefore preemptive, seeking to stop a form of discrimination that may pose a problem in the future. The following Part explores why Congress decided to shift from a retrospective basis for antidiscrimination protection to a preemptive one.

### III. JUSTIFICATIONS FOR PREEMPTIVELY ENACTING GINA

Traditional antidiscrimination statutes looked to past discrimination to justify protecting against present and future discrimination. Because genetic-information discrimination was not yet happening to a significant degree, GINA's proponents used two distinct but related arguments to support preempting genetic-information discrimination: (1) a research justification and (2) an antidiscrimination justification.

#### A. Research Justification

According to the research justification, people were afraid of using genetic technology because they believed that insurance companies and employers might use that information to discriminate against them and their families. Well-documented public fear existed around genetic testing. Research presented to Congress indicated that 93 percent of Americans believed that health insurers and employers should not be able to use genetic information in making decisions.<sup>164</sup> Likewise, almost the same percentage feared that the negative results of a genetic test could harm them, and nearly half of Americans reported this as a serious concern.<sup>165</sup> Anecdotal evidence from medical professionals supported the position that the fear of discrimination tempered the population's interest in genetic testing.<sup>166</sup> Moreover, this

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164. *Protecting Workers From Genetic Discrimination: Hearing Before H. Comm. on Energy & Commerce Subcomm. on Health*, 110th Cong. 110–15 (2007) (testimony by Kathy Hudson, Founder & Director of the Genetics and Public Policy Center) [*hereinafter* Testimony of Kathy Hudson]; see also Daniel Schlein, *New Frontiers for Genetic Privacy Law: The Genetic Information Nondiscrimination Act of 2008*, 19 GEO. MASON U. CIV. RTS. L.J. 311, 315 (2009) (noting surveys showing that the public remains “wary” of genetic data misuse).

165. Testimony of Kathy Hudson, *supra* note 164 (indicating that more than 90 percent of Americans are concerned that the results of their genetic tests could be misused and that as a result they would either forgo genetic testing or go out of their way to keep results confidential).

166. Bernstein, *supra* note 152, at 261 (noting that “research has shown that fear of genetic discrimination by insurers and employers is the primary barrier against testing”); Email from John Quillin, Genetic Counselor, to Amanda K. Sarata (Sept. 9, 2004), in PUBLIC PERSPECTIVES, *supra* note 120, at 93.

fear was intergenerational. Genetic testing not only affects the person being tested, but that person's whole family.<sup>167</sup> Thus, people feared that, if they tested positive for a genetic marker linked to any number of diseases, their decision to undergo genetic testing could negatively impact their loved ones.<sup>168</sup> Representative Louise Slaughter, therefore, described the decision to undergo genetic testing as "a Hobson's choice between learning vital health information and risking [one's] health insurance."<sup>169</sup> Thus, one explanation for the current absence of discrimination is simply that genetic information is not readily available to possible discriminators because most people are too afraid to take genetic tests.

Proponents of protecting genetic information argued that the fear of genetic testing was negatively impacting genetic research. Scientific advancement requires clinical studies. However, the fear of genetic-information discrimination was preventing many potential research subjects from participating in studies, thereby slowing the rate at which genetic technology could progress.<sup>170</sup> As a result, the biotech industry hoped that GINA might relieve anxieties around genetic testing, so that new genetic testing products might flourish.<sup>171</sup> Advocates, therefore, argued that public fear created a serious impediment to genetic science because people were too frightened to undergo testing.<sup>172</sup>

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167. Park, *supra* note 6 (quoting Dr. Kent McKelvey) (explaining that genetic testing "automatically affects your family members and that is fundamentally different from traditional medical tests").

168. See, e.g., Sen. Olympia J. Snowe, *Genetic Non-Discrimination—Time to Act to Protect Our Privacy*, U.S. FED. NEWS, July 16, 2004 (discussing a letter from a constituent explaining the constituent's decision to forgo genetic testing based on her fear that the results might negatively affect her daughter); Testimony of Carolina Hinestrosa (Oct. 18–19, 2004), in PUBLIC PERSPECTIVES, *supra* note 120, at 10 (discussing personal experience as a breast cancer survivor who avoided genetic testing for fear of its impact on her daughter).

169. 144 CONG. REC. H3,262 (daily ed. May 14, 1998) (statement of Rep. Slaughter).

170. Statement of Karen Rothenberg, *supra* note 123 (explaining that "[t]he tremendous promise of genetics is hamstrung by fear"); see also 79 Fed. Reg. 9056, 9057 (Mar. 2, 2009) (to be codified at 29 C.F.R. pt. 1635); Genetics and Public Policy Center, U.S. Public Opinion on Uses of Genetic Information and Genetic Discrimination (Apr. 24 2007), [http://www.dnapolicy.org/resources/GINAPublic\\_Opinion\\_Genetic\\_Information\\_Discrimination.pdf](http://www.dnapolicy.org/resources/GINAPublic_Opinion_Genetic_Information_Discrimination.pdf) (discussing negative impact of public fear of genetic testing on advances in genetic research).

171. See generally Maloyre Allison, *Industry Welcomes Genetic Information Nondiscrimination Act*, 26 NATURE BIOTECHNOLOGY 596, 596–97 (2008) (discussing positive reaction of genetic testing industry to passage of GINA).

172. See, e.g., *Senate Passes Bill Barring Genetic Discrimination*, ISS. SCI. & TECH. 21, 21 (2004) (quoting Sen. Bill Frist as saying, "The fear of genetic discrimination has the potential to prevent individuals from participating in research studies, from taking advantage of new genetic technologies, or even from discovering that they are not at high risk for genetically related illnesses"); Rep. Zach Wamp, *A Looking Into Your Future Health?*, WASH. TIMES, Jan. 5, 2004, at A15 (arguing that federal genetic nondiscrimination legislation was key to insuring that

In addition to stalling genetic science, supporters of genetic antidiscrimination legislation also maintained that the fear of genetic tests was harming the general public—people were not seeking diagnoses and treatments that could improve or sustain their health.<sup>173</sup> For example, one-third of the women offered a genetic test related to breast cancer declined, citing potential discrimination as the reason.<sup>174</sup> This study indicates that people were foregoing genetic tests that could lead to the prevention or early detection of serious health conditions because of fear, thereby possibly compromising the level of treatment and care available to them.

Not surprisingly, Congress explained in its findings that GINA “is necessary to fully protect the public from discrimination and allay their concerns about the *potential* for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies.”<sup>175</sup> Similarly, speaking out in favor of genetic antidiscrimination legislation, Senator Judd Gregg explained the dual goals of alleviating fear: “Fear of discrimination threatens

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“Americans . . . reap the benefits of the genomic era”); *Sen. Gregg Pushes for Protection of Patients from Genetic Discrimination*, U.S. FED. NEWS, July 22, 2004 (quoting Sen. Gregg as saying that federal legislation was necessary to securing our “ability to use new genetic technologies to improve human health and the scientific community’s ability to conduct research needed to understand, treat and prevent disease”). The National Human Genome Research Institute, which lobbied for the legislation, identified the fear of genetic discrimination as one of the major obstacles to realizing the benefits of the Human Genome Project and other advances in genetic science. National Human Genome Research Institute, Genetic Discrimination, <http://www.genome.gov/10002077> (last updated Sept. 21, 2009).

173. See Payne, *supra* note 117, at 38. Anita Silvers and Michael Stein also discuss the research justification in their 2002 piece in the *VANDERBILT LAW REVIEW*. See Anita Silvers & Michael Ashley Stein, *An Equality Paradigm for Preventing Genetic Discrimination*, 55 *VAND. L. REV.* 1341, 1351 (2002).

174. Standards for Privacy for Individually Identifiable Health Information, 65 *Fed. Reg.* 82,462, 82,466 (Dec. 28, 2000) (to be codified at 45 C.F.R. pts. 160 and 164) (quoting Sen. Patrick Leahy).

175. Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 *Stat.* 881 § 2(5) (2008) (emphasis added). The EEOC reiterated Congress’s purpose in its proposed rules, released March 2, 2009. 79 *Fed. Reg.* 9056, 9057 (Mar. 2, 2009) (to be codified at 29 C.F.R. pt. 1635):

Many genetic tests now exist that can inform individuals whether they may be at risk for developing a specific disease or disorder. But just as the number of genetic tests increase, so do the concerns of the general public about whether they may be at risk of losing access to health coverage or employment if insurers or employers have their genetic information. Congress enacted GINA to address these concerns, by prohibiting discrimination based on genetic information and restricting acquisition and disclosure of such information, so that the general public would not fear adverse employment- or health coverage-related consequences for having a genetic test or participating in research studies that examine genetic information.

society's ability to use new genetic technologies to improve human health and the scientific community's ability to conduct research needed to understand, treat and prevent disease."<sup>176</sup> Thus, the purpose behind allaying the population's fear of discrimination on the basis of genetic information was twofold: fear was both (1) impeding the advancement of genetic technology because people were unwilling to participate in clinical studies and other research and (2) stopping people from taking advantage of medical services that might have the ability to extend or save their lives.<sup>177</sup>

Relieving the fear of genetic-information discrimination, therefore, has both research-oriented and altruistic ends.<sup>178</sup> Interestingly, whether the concerns regarding genetic testing are genuine or merely perceived is irrelevant: the goal of the legislation was not to stop discrimination but rather to alleviate fear, and in so doing, to advance genetic science and personal health.<sup>179</sup>

176. *Sen. Gregg Pushes for Protection of Patients from Genetic Discrimination*, *supra* note 172.

177. A representative of the National Human Genome Institute described how fear and its impact on genetic science was GINA's true target:

The prevalence of genetic discrimination by insurance companies does not appear to be the key issue. The real issue is that the public perceives that the potential for discrimination by insurance companies is an overwhelming risk and in my experience this fear provides a barrier to genetics research and clinical genetics care. This barrier limits our potential for research in basic sciences and social and behavioral research. The greatest tragedy, however, is the missed opportunity to prevent cancer or diagnose it early in persons at high risk who are unwilling to risk the potential of discrimination.

PUBLIC PERSPECTIVES, *supra* note 120, at 81 (testimony of Don Hadley, Associate Investigator with the Social Behavioral Research Branch, Genetic Counselor with the Office of the Clinical Director of the National Human Genome Research Institute); *see also* JONES & SARATA, *supra* note 5, at Summary (noting problem of public fear as to misuse of genetic information and potential for discrimination); *Protecting Workers From Genetic Discrimination: Hearing Before H. Comm. on Energy & Commerce Subcomm. on Health*, 110th Cong. 110–15 (2007) (testimony of Karen Pollitz, Research Professor, Georgetown University Health Policy Institute) (same); Letter from Michael O. Leavitt to Reed V. Tuckson (Nov. 8, 2005); PUBLIC PERSPECTIVES, *supra* note 120, at 20–21 (statement of Carolina Hinestrosa) (attesting to personal experience with fear as to potential consequences of genetic testing); *Senate Passes Bill Barring Genetic Discrimination*, *supra* note 172 (noting negative consequences of public fear of genetic information misuse and discrimination based on such information).

178. *See* Miller, *supra* note 160, at 234 (noting that the “[r]efusal to submit to genetic tests due to fear of discrimination results in negative consequences both for the individuals who do not get tested and for the advancement of scientific research in this area”); Rivka Jungreis, *Fearing Fear Itself: The Proposed Genetic Information Nondiscrimination Act of 2005 and Public Fears About Genetic Information*, 15 J.L. & POL’Y 211, 244 (2007) (observing that assuaging public fear of genetic testing will benefit society “in two spheres—that of the advancement of scientific research, and that of the individual’s pursuit of optimal healthcare”).

179. *See* MICHELE SCHOONMAKER & ERIN WILLIAMS, CONGRESSIONAL RESEARCH SERVICE REPORT, NO. RL32478, GENETIC TESTING: SCIENTIFIC BACKGROUND AND NONDISCRIMINATION LEGISLATION 2 (updated Feb. 14, 2005) (“Despite the fact that few cases of genetic discrimination

*B. Antidiscrimination Justification*

Yet science was not the only justification for protecting genetic information. GINA's proponents heralded the law as "the first civil rights act of the 21st Century."<sup>180</sup> Characterizing GINA as a "civil rights act" implies that more was at stake than simply ameliorating fears that could impede medical research.

Insurers and employers use personal information to make decisions every day. Yet, for those decisions to constitute "discrimination" in the pejorative sense, people must believe that using that particular information is somehow inappropriate. According to GINA's supporters, making decisions based on genetic information is just such a scenario. When testifying before Congress, Dr. Francis Collins, the director of the National Genome Research Institute explained, "[W]hile genetic information and genetic technology hold great promise for improving human health, they can also be used in ways that are fundamentally unjust. Genetic information can be used as the basis for insidious discrimination."<sup>181</sup> Yet what makes decisions based on genetic information "fundamentally unjust"?<sup>182</sup>

While this fact may change as genetic technology continues to advance,<sup>183</sup> at present, genes are largely determined before birth and

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can be documented, proponents believe that the new legislation is needed to allay the fears of individuals about the potential for discriminatory practices so that they can seek beneficial health services, participate in much-needed clinical research, and otherwise reap the benefits of the publically funded Human Genome Project (HGP)."). When the goal is relieving fear, it does not matter if that fear is real or imagined. See Bernstein, *supra* note 152, at 288 (noting that in the context of AIDS testing "reducing the actual level of risk would not necessarily reduce the perceived risk").

180. Sen. Gregg *Pushes for Protection of Patients from Genetic Discrimination*, *supra* note 172 (quoting Sen. Judd Gregg); see also Press Release, U.S. Senate, Kennedy, Enzi, Snowe Celebrate Passage of Genetic Information Nondiscrimination Act (Apr. 24, 2008), available at [http://enzi.senate.gov/public/index.cfm?FuseAction=NewsRoom.NewsReleases&ContentRecord\\_id=86aa689b-802a-23ad-425c-6c6481cb42d2&Region\\_id=&Issue\\_id=](http://enzi.senate.gov/public/index.cfm?FuseAction=NewsRoom.NewsReleases&ContentRecord_id=86aa689b-802a-23ad-425c-6c6481cb42d2&Region_id=&Issue_id=) (quoting Sen. Kennedy as calling GINA "the first major . . . civil rights bill of the new century").

181. JONES & SARATA, *supra* note 5 (quoting Dr. Francis S. Collins, testimony given in 2000 before Senate Committee on Health, Education, Labor, and Pensions (citation omitted)); see also Harmon, *supra* note 57 ("Democrats and Republicans alike cited anecdotes and polls illustrating that people feel they should not be penalized because they happened to be born at higher risk for a given disease.").

182. For more on the perceived unfairness of genetic-information discrimination, see Jeffrey S. Morrow, *Insuring Fairness: The Popular Creation of Genetic Antidiscrimination*, 98 GEO. L.J. 215 (2009).

183. According to congressional testimony of Dr. Francis Collins, director of the National Genome Research Institute in 2003, within ten years, genetic researchers at the time hoped to be able to use gene therapy to treat a small number of conditions. See *The National Institutes of Health: Decoding Our Federal Investment in Genomic Research: Hearing before H. Comm. on*



subsequently remain outside of our control<sup>184</sup> (or at least extremely difficult to alter<sup>185</sup>). As a result, scholars and advocates have argued that genetic information warrants protection because it is an immutable characteristic.<sup>186</sup>

When invoked within antidiscrimination law, immutability stands for the proposition that entities should not discriminate on the basis of traits that a person did not choose and cannot change or control without serious cost.<sup>187</sup> Not coincidentally, the perceived

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*Energy and Commerce Subcomm. on Health*, 108th Cong. 108–23 (2003) (testimony of Francis Collins). However, by 2020, Dr. Collins predicted that a number of what he called “gene-based designer drugs” would be available to treat a number of conditions, including diabetes, Alzheimer’s, and hypertension. *Id.*

184. SCHOONMAKER & WILLIAMS, *supra* note 179, at 14 (“Individuals cannot help or change their inherited genetic make-up (at least with today’s scientific capabilities).”).

185. Most gene therapy is somatic: it involves inserting therapeutic genes into the body cells of a patient. For example, doctors could insert missing genes into a patient’s extracted white blood cells, cultivate more blood cells in a lab, and then re-administer the genetically altered cells to treat genetic immunodeficiency disorders. While germ-line gene therapy—inserting therapeutic genes into sperm or egg cells—is the subject of research, this practice is not being applied to human beings, at least for the time being. Regardless, it appears that while we may be able to change our genes before fertilization—or perhaps even in the very early stages of gestation—once an organism begins to form, and certainly by the time it decides to apply for a job or select health insurance, genetic material remains largely inalterable.

186. *See, e.g.*, Alexandra K. Glazier, *Genetic Predispositions, Prophylactic Treatments & Private Health Insurance: Nothing is Better Than A Good Pair of Genes*, 23 AM. J.L. & MED. 45, 53 (1997) (arguing that “[a] defective gene is thus more akin to an immutable characteristic than to an active disease”); Monique K. Mansoura & Frances S. Collins, “Testing & Telling?": *Implications for Genetic Privacy, Family Disclosure & the Law*, 1 J. HEALTH CARE L. & POL’Y 329, 351 (1998) (arguing that a decision based on genetic information, which is “inherited and immutable[,] is simply wrong”); Christine Formas Norris, *The Genetic Information Nondiscrimination Act of 2008: History, Successes, and Future Considerations*, 7 U. MD. L.J. RACE, RELIGION, & GENDER 192, 195 (2007) (asserting that “our genetic profiles are immutable characteristics, because much like race and gender, our genes are inherited and unalterable”); *see also Protecting Workers From Genetic Discrimination: Hearing Before H. Comm. on Educ. & Labor Subcomm. on Health, Employment, Labor & Pensions*, 110th Cong. 110-1 (2007) (testimony by Harriet Pearson, Chief Privacy Officer, IBM Corp.) [hereinafter Testimony of Harriet Pearson] (maintaining that “a person’s genetic profile is as natural and as inseparable from whom [sic] they are as any other physical trait or attribute.”).

187. Erwin Chemerinsky notes the moral inclination that “it is unfair to discriminate against people for a characteristic that is acquired at birth and cannot be changed.” ERWIN CHEMERINSKY, *CONSTITUTIONAL LAW: PRINCIPLE & POLICIES* 551 (1997). Similarly, Robert Post has observed that “[t]he unfairness of prejudice is particularly manifest when it is directed against immutable traits, like race or sex.” Robert Post, *Prejudicial Appearances: The Logic of American Antidiscrimination Law*, 88 CAL. L. REV. 1, 8 (2000). More recently, Ed Stein mapped the salience of “born that way” and “not a choice” arguments in favor of protecting sexual orientation. Ed Stein, *Born that Way? Not a Choice?: Problems with Biological and Psychological Arguments for Gay Rights* 9 (Cardozo Legal Studies Working Paper No. 223, 2008), available at <http://ssrn.com/abstract=1104538>. Courts have at times adopted the reasoning. *See, e.g.*, *DeNovellis v. Shalala*, 124 F.3d 298, 314 (1st Cir. 1997) (“If America stands for anything in the world, it is fairness to all, without regard to race, sex, ethnicity, age, or other immutable characteristics that a person does not choose and cannot change.”).

immutability<sup>188</sup> of race,<sup>189</sup> sex,<sup>190</sup> national origin,<sup>191</sup> disability,<sup>192</sup> and even age<sup>193</sup> has been cited as a reason for protecting those traits. (The major exception to the immutability norm in antidiscrimination law is, of course, religion.<sup>194</sup>)

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188. Importantly, I am not stating that any one of these categories is in fact immutable. Disability, for example, can be completely temporary. I am merely noting that immutability has at various times been used to justify protection.

189. When discussing Title VII in *Fagan v. National Cash Register Co.*, the D.C. Circuit stated that “Congress has said that no exercise of that responsibility may result in discriminatory deprivation of equal opportunity because of *immutable* race, national origin, color, or sex classification.” 481 F.2d 1115, 1125 (D.C. Cir. 1973) (emphasis in original).

190. The Fifth Circuit held that “distinctions in employment practices between men and women on the basis of something other than *immutable* or protected characteristics do not inhibit employment opportunity in violation of [Title VII].” *Willingham v. Macon Tel. Publ’g Co.*, 507 F.2d 1084, 1091 (5th Cir. 1975) (emphasis added).

191. In *Garcia v. Gloor*, the Fifth Circuit cited immutability as a justification for protection of national origin, as well as other Title VII categories. 618 F.2d 264, 269 (5th Cir. 1980) (“Save for religion, the discriminations on which the Act focuses its laser of prohibition are those that are either beyond the victim’s power to alter, or that impose a burden on an employee on one of the prohibited bases. No one can change his place of birth (national origin), the place of birth of his forebears (national origin), his race or fundamental sexual characteristics.”).

192. When Congress initially passed GINA in 1990, it was explicit regarding the role of immutability in protecting people with disabilities, stating in its findings in support of the ADA that people with disabilities have suffered discrimination “based on characteristics that are *beyond the control of such individuals*.” Americans with Disabilities Act of 1990, ch. 126, 42 U.S.C. § 12101(a)(7) (emphasis added), *removed by the Americans with Disabilities Amendments Act*, Pub. L. No. 110-325, 122 Stat. 3557 (enacted 2008).

193. Despite age’s ever-changing status, some courts have nonetheless held that it is an immutable trait on par with race and sex. For example, in describing the passing of ADEA, the Third Circuit explained that “[a]ge became a proscribed basis for employment decisions in much the same manner as Title VII of the 1964 Civil Rights Act had earlier prohibited employment discrimination on the basis of *other immutable* personal characteristics such as race, color, religion, sex or national origin.” *Rodriguez v. Taylor*, 569 F.2d 1231, 1236 (3d Cir. 1977) (emphasis added). Judge Garth of the D.C. Circuit made a similar point in a 1988 dissenting opinion. *See Arnold v. U.S. Postal Serv.*, 863 F.2d 994, 1004 (D.C. Cir. 1988) (Garth, J., dissenting). (“[U]nder Title VII, Congress has decreed that certain adverse employment decisions made by employers based on an individual’s possession of any of these characteristics, is repugnant and illegal. In enacting the ADEA, Congress has also decreed that employment decisions based on age, (an equally immutable characteristic), are similarly repugnant and illegal.”). Similarly, the First Circuit has grouped age with race, sex, and ethnicity as characteristics worthy of protection because they are characteristics that “a person does not choose and cannot change.” *DeNovellis v. Shalala*, 124 F.3d 298, 314 (1st Cir. 1997).

194. I do not discuss religion at length because courts do not link the protection of religion to its immutability. However, scholars have noted that certain other requirements have periodically functioned like immutability. *See, e.g., Karen Engle, The Persistence of Neutrality: The Failure of the Religious Accommodation Provision To Redeem Title VII*, 76 TEX. L. REV. 317, 373 (1997) (arguing that an institutional religion vs. personal preference dichotomy has sometimes functioned like immutability); Jamie Darin Prenkert & Julie Manning Magid, *A Hobson’s Choice Model for Religious Accommodation*, 43 AM. BUS. L.J. 467, 501 (2006) (noting that the sincerity requirement in religion cases approximates the role of immutability).

A number of GINA's proponents explicitly cited immutability to justify protecting genetic information.<sup>195</sup> For example, Senator Snowe explained that "[g]enetic discrimination is, by its nature, a purposeful act based on an immutable fact—one's very heredity."<sup>196</sup> Likewise, in a hearing before Congress, one lawyer maintained that genetic information warranted antidiscrimination protection because "we are born with our 46 chromosomes and 30,000 genes. We cannot control or change them."<sup>197</sup> Representative Slaughter echoed this sentiment, opining that "[n]o American[s] should have to worry that their genes—which they did not choose, and over which they have no control—will be used against them."<sup>198</sup> Personal anecdotes reinforced this position. One woman relayed her experiences with genetic-information discrimination in a letter: "I learned that not only was I a carrier for Hemophilia (which was not my fault or choice), but that I had a 50% chance of inheriting Huntington's Disease as well (not my fault or choice)."<sup>199</sup>

Despite recent arguments in favor of protecting genetic information, many have questioned immutability's role in antidiscrimination law.<sup>200</sup> In 1980, John Hart Ely attacked the idea that courts should consider immutability when determining whether a group warrants heightened equal protection scrutiny. He argued that decisionmakers can cherry pick when immutability matters by linking

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195. Jeffrey S. Morrow also notes the role of immutability in the perceived unfairness of genetic-information discrimination. See Morrow, *supra* note 182, at 234–37. I, however, disagree with his characterization of an immutability model as "disability model," *id.* at 236, given that disability antidiscrimination protection is not grounded in blamelessness but rather in a culture of exclusion. The ADA protects a paraplegic regardless of whether she acquired her impairment as an innocent bystander or a drunk-driver. She need only demonstrate a substantially limiting impairment. See 42 U.S.C. § 12102(2) (defining "disability" under the ADA).

196. Press Release, Office of Sen. Olympia Snowe, Senate Passes Snowe Bill Banning Genetic Discrimination by Insurers, Employers (Feb. 18, 2005), available at [http://snowe.senate.gov/public/index.cfm?FuseAction=PressRoom.PressReleases&ContentRecord\\_id=df2ebbd7-f4e9-4301-bef4-7231b2d5cdfb&Region\\_id=&Issue\\_id=](http://snowe.senate.gov/public/index.cfm?FuseAction=PressRoom.PressReleases&ContentRecord_id=df2ebbd7-f4e9-4301-bef4-7231b2d5cdfb&Region_id=&Issue_id=)

197. *Protecting Workers From Genetic Discrimination: Hearing Before H. Comm. on Energy & Commerce Subcomm. on Health*, 110th Cong. 110–15 (2007) (statement of Frank Swain).

198. 143 CONG. REC. E12 (1997) (statement of Rep. Louise Slaughter—Extension of Remarks).

199. Letter from Michelle Thompson (Sept. 22, 2004), in PUBLIC PERSPECTIVES, *supra* note 120, at 65.

200. In fact, the role of immutability in antidiscrimination law has been so deeply criticized that over a decade ago, Kenji Yoshino compared discussing immutability as "tantamount to cataloguing new ways to flog a dying horse." Kenji Yoshino, *Assimilationist Bias in Equal Protection: The Visibility Presumption and the Case of "Don't Ask, Don't Tell"*, 108 YALE L.J. 485, 491 (1998).

the immutable trait to some sort of legitimizing purpose.<sup>201</sup> Similarly, critics of GINA noted how the selective use of immutability led Congress to protect genetic information but not other types of immutable characteristics that increase one's proclivity for developing a particular disease or disorder.<sup>202</sup>

However, the research justification for GINA went beyond immutability. Although people do not choose and cannot change their genes, Congress wanted to motivate those individuals who were foregoing genetic testing out of fear to use available medical services and participate in research. Offering antidiscrimination protections for genetic information was essential to making people feel comfortable with taking genetic tests.<sup>203</sup> As a result, Congress could encourage the use of genetic technology by protecting those immutable traits. The two justifications for passing GINA—research and antidiscrimination—are, therefore, inextricably related.

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201. Ely asserted that:

[N]o one has bothered to build the logical bridge, to tell us exactly *why* we should be suspicious of legislatures that classify on the basis of immutable characteristics. Surely one has to feel sorry for a person disabled by something that he or she can't do anything about, but I am not aware of any reason to suppose that elected officials are unusually unlikely to share that feeling. Moreover, classifications based on physical disability and intelligence are typically accepted as legitimate, even by judges and commentators who assert that immutability is relevant. The explanation, when one is given, is that *those* characteristics (unlike the one the commentator is trying to render suspect) are often relevant to legitimate purposes. At that point there's not much left of the immutability theory, is there?

JOHN HART ELY, *DEMOCRACY AND DISTRUST: A THEORY OF JUDICIAL REVIEW* 150 (1980); *see also* Morrow, *supra* note 182, at 241–44 (discussing the malleable nature of immutability); Camille Gear Rich, *Performing Racial and Ethnic Identity: Discrimination by Proxy and the Future of Title VII*, 79 N.Y.U. L. REV. 1134, 1141 (2004) (arguing “that the courts’ focus on the biological/voluntary distinction is fundamentally unprincipled and illogical, as the discriminatory animus in cases involving so-called biological racial or ethnic traits and voluntary, performed racial or ethnic traits operates identically”).

202. *Congress Restricts Use of Genetic Information by Insurers & Employers*, 122 HARV. L. REV. 1038, 1041 (2009) [hereinafter *Congress Restricts Use*] (“[GINA] implies and promotes genetic exceptionalism—the idea that genetic information needs special treatment—despite lacking a sound basis for separating genetic conditions from nongenetic ones that people did not knowingly cause and cannot change.”); *see also* Sonia M. Suter, *The Allure and Peril of Genetic Exceptionalism: Do We Need Special Genetics Legislation?*, 79 WASH. U. L.Q. 669, 712 (2001) (“Although we cannot control the genes we inherit, we cannot control a great many other risk factors, such as in utero exposures, environmental conditions, or drunk drivers, which may have profound effects on our future health.”).

203. *See* Testimony of Harriet Pearson, *supra* note 186:

By firmly establishing that none of us can be discriminated against on the basis of the genes we are born with and have no real control over, we also will create the safe foundation for future therapies that could repair or address the genetic defect that might make us prone to particular diseases or ailments.

Having established the reasons behind enacting GINA preemptively, the next Part of this Article proceeds to examine the normative implications of preemptive antidiscrimination legislation.

#### IV. IMPLICATIONS OF PREEMPTIVELY ENACTING GINA

Because GINA is perhaps the first preemptive antidiscrimination statute in American legal history, the effect that an absence of existing discrimination will have is unclear. There are definite benefits to preempting discrimination—such as effectively stopping discrimination before it starts—but also inherent difficulties.

##### *A. Fear as a Basis for Law*

One important theoretical question surrounding preemptive legislation is whether the fear that something that does not pose a significant current threat but *may* become one in the future should ever form the basis of a law. GINA's adversaries maintained that fear should not justify an antidiscrimination statute,<sup>204</sup> criticizing the anxieties over genetic-information discrimination as completely unfounded. Not only was discrimination simply not happening,<sup>205</sup> they argued, but nothing indicated that insurers and employers would ever discriminate on the basis of genetic information if given the opportunity.<sup>206</sup> Opponents criticized the "anecdotal but apocryphal stories," such as the more than decade-old *Burlington Northern* case, as feeding the public's irrational fears.<sup>207</sup> Proponents countered with evidence implying that the anxiety surrounding genetic testing has

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204. In reference to fear as a primary justification for GINA, Fishman stated "That is not how Congress has responded in the past and should not be how Congress responds today. Fear should not be the predicate for federal legislation." Statement of Burton J. Fishman, *supra* note 45.

205. See *supra* Section II(B)(2) for the discussion of a lack of a history of genetic discrimination.

206. Philip R. Reilly, *Genetic Discrimination*, in GENETIC TESTING AND THE USE OF INFORMATION 106 (Clarisa Long ed., 1999) ("[L]ittle evidence supports the widespread fear that people who undergo genetic tests to determine whether they are at increased risk for developing a serious disorder face a significant risk of genetic discrimination."); see also Bernstein, *supra* note 152, at 245 ("Genetic discrimination is rare and apparently on the decline. Potential abusers, such as employers and insurers, do not use genetic information."); Diver & Manslow-Cohen, *supra* note 114, at 1464 ("It is true, of course, that group-based discrimination can persist in competitive labor markets, as the history of race-based and gender-based employment discrimination vividly demonstrates. But that undeniable—and undeniably deplorable—fact does not furnish a basis for predicting a similar pattern of irrational discrimination by genotype.")

207. Statement of Burton J. Fishman, *supra* note 45.

the possibility to become a practical reality.<sup>208</sup> Yet, on some level, it doesn't matter if the fear is founded or unfounded, so long as it has the effect of altering behavior—such as encouraging genetic testing.<sup>209</sup>

One difficulty about legislating preemptively stems from the inability to predict the future accurately. Philosopher Hans Jonas proposed ethical guidelines to account for our limited—and inevitably flawed—predictive scientific knowledge.<sup>210</sup> According to Jonas, we cannot accurately know the future results of our present actions, the conditions under which our descendants will live, or the norms future generations will value.<sup>211</sup> Thus, it comes as no surprise that one criticism of basing an antidiscrimination statute on fear was that Congress is incapable of anticipating how the discrimination will actually operate if it indeed occurs.<sup>212</sup> Moreover, preemptive legislation could swiftly become obsolete or even detrimental.<sup>213</sup>

However, the inability to predict future outcomes does not imply that scientific advances always should go unchecked. Scientists conducting research and creating technology may not be as aware—or as wary—of the potential problems posed by their discoveries. Richard Posner has noted that “[s]cientists want to advance scientific

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208. Amy Harmon, *Fear of Insurance Trouble Leads Many to Shun or Hide DNA Tests*, N.Y. TIMES, Feb. 24, 2008, at A1 (citing a 2008 Georgetown University Health Policy Institute study indicating that in seven of ninety-two hypothetical underwriting decisions, insurers would deny coverage, charge more, or exclude some conditions based on genetic tests).

209. Letter from Reed V. Tuckson, Chair, Sec'y's Advisory Comm. on Genetics, Health, and Soc'y, to Michael O. Leavitt, Sec'y of Health and Human Servs. (May 3, 2005):

The Committee was influenced above all by the views and concerns we heard from patients and the general public. Their testimony made it abundantly clear that there are deep-seated fears about the potential for misuse of genetic information in health insurance and employment and that the public is concerned about the lack of specific Federal legal protections against genetic discrimination. Moreover, the public testimony documented that in many cases, healthcare decisions are being shaped by fear rather than best medical practice.

See also Bernstein, *supra* note 152, at 288 (explaining that “need to influence the public perception of risk is, therefore, particularly crucial in the case of preventive and non-triable technologies, such as genetic testing”).

210. HANS JONAS, *THE IMPERATIVE OF RESPONSIBILITY: IN SEARCH OF AN ETHICS FOR THE TECHNOLOGICAL AGE* 38–46 (1984).

211. *Id.*

212. Erin Heath, *Zippering Up Genes Discrimination*, NAT'L J., July 21, 2001 (quoting Prof. Mark Hall, Wake Forest Univ.) (“It’s difficult to craft legislation in advance of the problem arising, because you don’t fully know the dimensions of the problem.”).

213. During a hearing on GINA, a lawyer noted that “[t]oday’s genetic nondiscrimination legislation may quickly become outdated, and indeed counterproductive to its original purpose . . . .” *Genetic Nondiscrimination: Implications for Employers and Employees: Hearing Before H. Comm. on Energy & Commerce Subcomm. on Employer-Employee Relations, Comm. on Educ. & the Workforce*, 107th Cong. 75 (2001) (statement of Harold P. Coxson).

knowledge rather than to protect society from science; the policy maker's ordering of values is the reverse. Not that scientists are indifferent to public safety; but it is not their business and sometimes it is in competition with their business."<sup>214</sup> In short, scientists want what is best for science, not necessarily what is best for society. Consequently, Posner encourages lawyers and lawmakers to think in terms of prevention.<sup>215</sup>

Preventative legal protections, however, should not go forward unfettered. Cass Sunstein has suggested implementing an "Anti-Catastrophe Principle" to target the most serious risks by identifying the worst-case scenarios and then taking regulatory action to reduce those risks.<sup>216</sup> Under this principle, an effective preemptive strategy requires proposing cost-effective solutions, reducing the burdens on those least equipped to handle them, and being aware of the precaution's expense.<sup>217</sup> However, an individual who acts preemptively must also realize that eliminating some risks can create others.<sup>218</sup>

Although the situations described by Posner and Sunstein are life-threatening disasters,<sup>219</sup> their message is clear: lawmakers *should* sometimes intervene to alleviate fears associated with scientific discoveries, especially when the risk of serious harm is high and the cost of intervention is low. Thus, although we may lack perfect knowledge regarding how scientific advancements will impact society, there may be times when the law should alleviate fears associated with developing technology.

GINA provided an excellent opportunity for preemptive lawmaking. Like some of Posner's and Sunstein's catastrophic examples, genetic-information discrimination results directly from science. Discriminating on the basis of genetic information often relies on testing and scientific expertise,<sup>220</sup> making genetic-information

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214. RICHARD A. POSNER, *CATASTROPHE: RISK AND RESPONSE* 99 (2004).

215. *See generally id.*

216. CASS R. SUNSTEIN, *LAWS OF FEAR: BEYOND THE PRECAUTIONARY PRINCIPLE* 109, 114–15 (2005).

217. *Id.* at 114–15.

218. *Id.*

219. POSNER, *supra* note 214, at 30 (quoting MARTIN REES, *OUR FINAL HOUR: A SCIENTIST'S WARNING: HOW TERROR, ERROR, AND ENVIRONMENTAL DISASTER THREATEN HUMANKIND'S FUTURE IN THIS CENTURY—ON EARTH AND BEYOND* 120–21 (2003)).

220. *See Diver & Manslow-Cohen, supra* note 114, at 1445 ("One obviously cannot base discrimination on a person's genetic profile unless one has first obtained information about that profile."); David F. Partlett, *Misuse of Genetic Information: The Common Law and Professionals' Liability*, 42 *WASHBURN L.J.* 489, 489–91 (2003) ("Genetic information about individuals is almost exclusively created by the application of professional scientific skill. . . . In these contexts a professional has applied his expertise to the carrying out and interpretation of the genetic test."). The exception is that family history constitutes genetic information, which requires only

discrimination patently different from discrimination on the basis of race, sex, age, or disability.<sup>221</sup> To face the kind of discrimination covered by GINA, most individuals will have to opt-in to the category of potential victims by taking genetic tests. Because science created the category “genetic information,” it in effect created the potential for genetic-information discrimination. Thus, lawmakers arguably should intervene to protect society from the potentially negative results of these discoveries. However, preempting discrimination has both benefits and problems.

### *B. Benefits*

GINA has both economic and social benefits. From an economic perspective, the benefits posed by prohibiting genetic-information discrimination should outweigh the costs of enacting the law. First, GINA responds to two serious risks: a risk of discrimination and a risk that scientific research might stagnate due to the fear of genetic testing. Second, GINA’s expected costs are low. Congress estimated that passing GINA would have “no significant effect on direct spending.”<sup>222</sup> Additionally, insurers and employers do not yet have widespread access to genetic information, so the law does not restrict any deeply ingrained existing practices that would have to be changed. Furthermore, genetic-information discrimination is not yet happening on a significant scale, so no immediate litigation expenses should result. In fact, if the statute effectively preempts genetic-information discrimination, valid GINA claims may be exceedingly rare. Lastly, with regard to genetic-information discrimination, the interests of both science and society are aligned: GINA protects people from possible discrimination *and* advances science by alleviating fear that may have prevented clinical studies and further research. The fear of genetic-information discrimination was, therefore, an appropriate circumstance for enacting preemptive legislation.

From a social perspective, the greatest advantage of preemptively enacting GINA is preventing genetic-information

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the diagnosis of manifested condition in an individual’s family member, not the results of a genetic test. GINA, Pub. L. No. 110-233, 122 Stat. 881 §§ 101(a)(2), 102(a)(2), 103(a)(2), 104(b), 201(4)(A)(i)–(iii) (2008) (defining “genetic information”).

221. Norris, *supra* note 186, at 198 (“Unlike race, ethnicity, religion, or gender, genetic predispositions are not readily apparent without laboratory genetic testing, physical medical examinations, or the disclosure of family medical histories.”).

222. CONG. BUDGET OFFICE, COST ESTIMATE, H.R. 493, GENETIC INFORMATION NONDISCRIMINATION ACT OF 2007, at 1 (2007).



discrimination from ever taking root. One possible reason for the limited evidence of genetic-information discrimination is the absence of a cognizable class of genetically disadvantaged people. As mentioned in Part II, genetic science may not be yet at the point where our understanding of the connection between genetics and health is sufficient to create a genetic underclass. But even if we have arrived at that point, genetic testing is not sufficiently widespread for such a group to exist at present.

Regardless of whether the result of a lack of technology or of a lack of testing, GINA is currently without a recognized category of people targeted by its protections. Thus, GINA is perhaps the first antidiscrimination statute passed without an associated identity group. The absence of an existing socially recognized group means that there are no preconceived notions regarding that group. Importantly, without an established group, there can be no stigma involving group membership. Thus, perhaps the greatest benefit of preemptive genetic antidiscrimination legislation is that—if enacted swiftly—it could preempt the formation of underlying social stigma. Yet, while potentially successful in preempting discrimination, GINA is not without its flaws.

### C. Problems

GINA's preemptive nature generates two significant types of problems: enforcement problems and effectiveness problems. Thus, while GINA's preemptive quality might be the statute's biggest asset, it is also the statute's most pronounced weakness.

#### 1. Enforcement Problems

Perhaps the most daunting problem facing GINA is whether Congress has the authority to pass preemptive antidiscrimination legislation. Congress may only enact laws pursuant to its constitutionally enumerated powers.<sup>223</sup> While it did not specify under which power it passed GINA, Congress cited forced sterilization, racially driven sickle cell testing, and the *Norman-Bloodsaw* case as justifications for the legislation.<sup>224</sup> These examples imply that Congress passed GINA as a civil rights law pursuant to either Section

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223. *United States v. Morrison*, 529 U.S. 598, 607 (2000) ("Every law enacted by Congress must be based on one or more of its powers enumerated in the Constitution."); *Marbury v. Madison*, 5 U.S. (1 Cranch) 137, 176 (1803) ("The powers of the legislature are defined, and limited; and that those limits may not be mistaken, or forgotten, the constitution is written.").

224. See *supra* notes 121–123 and accompanying text.

5 of the Fourteenth Amendment or its Article I commerce power.<sup>225</sup> Consequently, the law may face several foreseeable challenges, particularly regarding its application to the states.<sup>226</sup>

The Commerce Clause gives Congress the power “[t]o regulate Commerce with foreign Nations, and among the several States, and with the Indian Tribes.”<sup>227</sup> The Supreme Court has held that Congress’s commerce power covers “channels of interstate commerce”; “instrumentalities of interstate commerce, or persons or things in interstate commerce, even though the threat may come only from intrastate activities”; and “those activities having a substantial relation to interstate commerce.”<sup>228</sup> While laws passed under Congress’s commerce power may apply to both state and private actors, the Court has held that laws falling solely under the Commerce Clause cannot abrogate state sovereign immunity in suits for damages.<sup>229</sup> Thus, absent a waiver of sovereign immunity, private litigants cannot recover against state defendants when suing for damages under a statute supported only by the commerce power.

Congress, however, may abrogate Eleventh Amendment sovereign immunity when passing Section 5 legislation.<sup>230</sup> Section 5 provides that “Congress shall have power to enforce [the substantive guarantees of the Fourteenth Amendment—including equal protection and due process], by appropriate legislation.”<sup>231</sup> Although capable of piercing the veil of sovereign immunity, Congress’s Section 5 power is not unlimited. Because the Fourteenth Amendment applies only to state actions, laws passed under Section 5 cannot prohibit private

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225. Civil rights legislation is often passed under these powers. *See, e.g.*, 42 U.S.C. § 12101(b)(4) (2000) (“It is the purpose of this Act . . . to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities.”).

226. For a more detailed analysis of GINA’s potential enforcement problems, see Harper Jean Tobin, *The Genetic Information Nondiscrimination Act of 2008: A Case Study of the Need for Better Congressional Responses to Federalism Jurisprudence*, 35 J. LEGIS. (forthcoming), available at [http://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=1375684](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1375684).

227. U.S. CONST. art. I, § 8, cl. 3.

228. *Morrison*, 529 U.S. at 609 (quoting *United States v. Lopez*, 514 U.S. 549, 558 (1995)).

229. *Seminole Tribe of Fla. v. Florida*, 517 U.S. 44, 72–73, 76 (1996). *But see* *Cent. Va. Cmty. Coll. v. Katz*, 546 U.S. 356, 379 (2006) (holding that Congress may abrogate sovereign immunity under the Bankruptcy Clause). While units of local governments qualify as state actors under the Fourteenth Amendment, the Eleventh Amendment does not protect them. *Univ. of Ala. v. Garrett*, 531 U.S. 356, 368–69 (2001). Thus, the Eleventh Amendment does not protect *all* state actors. The Commerce Clause legislation, therefore, applies to those unprotected state actors.

230. *Fitzpatrick v. Bitzer*, 427 U.S. 445, 456 (1976).

231. U.S. CONST. amend. XIV, § 5; *see also* *City of Boerne v. Flores*, 521 U.S. 507, 517 (1997).

conduct.<sup>232</sup> Additionally, laws enforced via Section 5 cannot redefine the substance of the underlying constitutional protections they seek to enforce.<sup>233</sup> Thus, Section 5 protections must be “congruent” and “proportional” to their Section 1 counterparts.<sup>234</sup>

The congruence and proportionality test proceeds in two parts: it begins with a determination of whether the legislation targets a pattern of constitutional wrongs, then it looks to whether the remedy is proportional to the statute’s remedial intent.<sup>235</sup> For example, in *University of Alabama v. Garrett*, state employees filed for damages under Title I of the ADA. The Supreme Court held that Title I of the ADA did not abrogate sovereign immunity.<sup>236</sup> The provision, however, appears to have remained valid, ostensibly under the Commerce Clause. The Court began its Section 5 analysis by examining the level of protection allocated to people with disabilities under Section 1.<sup>237</sup> After concluding that “rational basis” was the appropriate level of scrutiny, the Court turned to the first part of the congruence and proportionality test, examining “whether Congress identified a history and pattern of unconstitutional employment discrimination by the States against the disabled.”<sup>238</sup> Yet despite Congress’s efforts to establish a history of discrimination against people with disabilities, the Court ultimately concluded that “[t]he legislative record of the ADA . . . simply fails to show that Congress did in fact identify a pattern of irrational state discrimination in employment against the disabled.”<sup>239</sup> The absence of a history of discrimination, therefore, may invalidate Section 5 laws.

Although GINA’s drafters attempted to create a comprehensive law that applies to all varieties of health insurance and all facets of employment, GINA’s provisions may not withstand constitutional scrutiny. Given that GINA deals with health insurance and employment, the Court would likely uphold GINA under the Commerce Clause, because both substantive titles relate in some capacity to interstate commerce. Thus, the law would apply to actors

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232. *Morrison*, 529 U.S. at 621.

233. *Flores*, 521 U.S. at 519 (“Congress does not enforce a constitutional right by changing what the right is.”).

234. *Id.* at 520.

235. *Fla. Prepaid Postsecondary Educ. Expense Bd. v. Coll. Sav. Bank*, 527 U.S. 627, 639 (1999) (“[F]or Congress to invoke § 5, it must identify conduct transgressing the Fourteenth Amendment’s substantive provisions, and must tailor its legislative scheme to remedying or preventing such conduct.”).

236. *Univ. of Ala. v. Garrett*, 531 U.S. 356, 374 (2001).

237. *Id.* at 365–68.

238. *Id.* at 368.

239. *Id.*

not protected by Eleventh Amendment sovereign immunity. While Congress may pierce sovereign immunity under Section 5, GINA most likely would not satisfy the Court's congruence and proportionality test because of the limited evidence of existing genetic-information discrimination. Like people with disabilities, the genetically disadvantaged therefore would probably receive the lowest level of equal protection review.<sup>240</sup> Thus, the level of Section 1 protection enforced by GINA would most likely be at its constitutional nadir. More importantly, because GINA is largely preemptive, there is little evidence of a history and pattern of unconstitutional discrimination. GINA, therefore, would likely fail the first prong of the congruence and proportionality test, making it unenforceable against the states.<sup>241</sup>

In sum, regardless of how it is constitutionally authorized, GINA faces substantial limitations because of its preemptive qualities. If Congress passed GINA only pursuant to its commerce power, GINA would reach private actors, as well as state actors not within the scope of Eleventh Amendment protection. However, because Congress cannot abrogate sovereign immunity in suits for damages under its commerce power alone and because GINA would likely fail the congruence and proportionality test for Section 5 legislation, Title II may not apply to state employers in private suits for money damages.<sup>242</sup> GINA's preemptive nature at best limits how the law applies to certain state actors and at worse invalidates the law completely.

## 2. Effectiveness Problems

In addition to creating problems with enforcement, preemptively enacting legislation generates difficulties regarding the law's effectiveness. Because the legislation seeks to bypass future

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240. Jessica L. Roberts, *An Area of Refuge: Due Process Analysis & Emergency Evacuation for People with Disabilities*, 13 VA. J. SOC. POL'Y & L. 127, 137 (2005) (noting that the Supreme Court has not given a new group heightened scrutiny in over three decades).

241. Silvers & Stein, *supra* note 173, at 1376 ("There is, first, a question about how efficaciously federal antidiscrimination regulations can constrain states from discriminating against prospective and present employees on the basis of predictive genetic information. The Supreme Court has struck down the application of certain provisions of both the ADA (in *Board of Trustees v. Garrett*) and the Age Discrimination in Employment Act (in *Kimel v. Florida Board of Regents*) to states in view of their Eleventh Amendment immunity. In both these cases, the Court declared that Congress did not have sufficient evidence of pervasive historical discrimination on the proscribed basis by the states, which is the sole condition under which a civil rights approach can constrain state sovereignty. There is less historical evidence, not more, that states have discriminated on the basis of predictive genetic information.").

242. Title I does not pose as much of a problem because health insurance laws, such as ERISA, amended by GINA do not provide remedies for monetary damages.

discrimination—not to end existing discrimination—its success will be difficult to measure. If genetic-information discrimination erupts into an epidemic and litigants cannot prevail in their lawsuits, then the law quite clearly will have failed. On the contrary, if time passes and genetic-information discrimination never occurs on a major scale, two opposing scenarios will exist. Under one scenario, GINA's opponents were correct and the legislation was unnecessary, either because existing laws were doing the job or because health insurers and employers were not interested in genetic information after all. Under the other scenario, GINA was an immense victory and managed to preempt genetic-information discrimination before it ever occurred. Thus, because GINA attempts to preempt discrimination, we may never know if the statute was hugely successful or completely unnecessary.<sup>243</sup>

As discussed earlier,<sup>244</sup> Congress intended to alleviate the fear of discrimination. However, simply passing legislation may not end the anxieties surrounding genetic-information discrimination.<sup>245</sup> For example, assuming that GINA's advocates are correct and people are avoiding genetic testing out of fear of discrimination, the extensive state protections pre-GINA indicate that people may need more than legal protections to feel comfortable taking genetic tests. Furthermore, the research justification relies on the assumption that people are responding honestly to the survey questions when, in fact, their desire to bypass genetic testing may include other motivating factors apart from discrimination, such as the possible reaction of family members<sup>246</sup> or simply not wanting to know. Finally, additional survey research indicates that people may not have confidence in GINA's protections until it has been used in court.<sup>247</sup> Ironically, if GINA is truly successful as a statute, employers and health insurers will not discriminate,<sup>248</sup> leaving litigants limited opportunities to test the

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243. *Congress Restricts Use*, *supra* note 202, at 1042–43 (explaining that preempting genetic-information discrimination renders unknowable the potential severity of that discrimination had it gone unchecked); *see also* Blackwell, *supra* note 117, at 168 (asserting that given the lack of documented discrimination, GINA's protections maybe presently unnecessary).

244. *See supra* Part III.A.

245. *See* Blackwell, *supra* note 117, at 165 (noting that “[e]ven if GINA protects against potential genetic discrimination, this does not necessarily mean that the number of individuals who will participate in genetic testing will increase”).

246. *See* Payne, *supra* note 117, at 39 (suggesting that “psychological concern or concern about family members’ responses” might also be motivating factors).

247. MARILYN E. COORS, *THE MATRIX: CHARTING AN ETHICS OF INHERITABLE GENETIC MODIFICATION* 20–21 (2002).

248. One can imagine employers and health insurers hiring experts to avoid GINA violations. An over-enforcement problem might develop in which legal advisors admonish covered

statute. As a result, GINA may not have the desired effect of assuaging people's fears. Moreover, passing legislation may even *legitimate* those fears by implying that genetic information poses a greater threat than it actually does.<sup>249</sup> Preemptively enacting GINA may interfere with the statute's effectiveness not only by obscuring our ability to measure its success, but also by legitimizing the very fears it sought to relieve.

To conclude, preemptively enacting GINA carries both positive and negative implications. On the one hand, preemptive legislation allows Congress to bypass future discrimination. On the other, preemptive legislation gives rise to a unique set of problems that could affect both the statute's enforcement and effectiveness.

### CONCLUSION

Before GINA, four major statutes governed employment discrimination. Although they were different in construction and passed decades apart, Title VII, the ADEA, the Rehabilitation Act, and Title I of the ADA shared a similar purpose: to end a particular form of *existing* discrimination. The statutes were retrospective, justifying antidiscrimination protection based on histories of discrimination. Yet when GINA passed in 2008, little evidence indicated that genetic-information discrimination posed a historical—or even a current—threat. While GINA's opponents saw the absence of a history of discrimination as a major flaw, its advocates embraced the slim record as an exciting opportunity to preempt discrimination for the first time in American history.

The law's proponents cited two related reasons for enacting GINA preemptively: (1) alleviating public fear to advance scientific research and (2) the belief that it is fundamentally unfair to discriminate against individuals based on traits they did not choose and cannot change. In passing GINA, Congress hoped to encourage people to seek genetic testing without fear of discrimination.

GINA's preemptive nature truly makes the statute unique. GINA provides a novel opportunity to stop a new form of discrimination before it takes hold. Moreover, because a socially recognized group of genetically disadvantaged people does not currently exist, GINA can preempt not only discrimination but also

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entities to avoid all genetic testing, even pursuant to GINA's exceptions, thereby further limiting research participation.

249. *Congress Restricts Use*, *supra* note 202, at 1043; Bernstein, *supra* note 152, at 264 (noting that pre-GINA genetic antidiscrimination legislation actually increased fears because of the publicity surrounding those laws).

the formation of a new type of social stigma. However, preemptive lawmaking also has inherent problems. Most notably, GINA likely would not withstand analysis under Section 5 of the Fourteenth Amendment because of the lack of a well-established pattern of genetic-information discrimination. This potential failure calls into question Congress's authority to pass preemptive legislation. Additionally, because GINA is preemptive, it may be practically impossible to measure its true effectiveness. Sadly, GINA may fail to alleviate (or may even legitimize) fears of genetic-information discrimination. We will have to wait and see whether the positives of legislating preemptively outweigh the negatives. And even so, the fact that Congress preemptively enacted GINA does not ensure that we will see other preemptive legislation in the future.

Recent developments indicate that GINA is merely the exception to the well-established practice of retrospective lawmaking. In January 2009, President Obama signed the Lilly Ledbetter Fair Pay Act.<sup>250</sup> That new law overturned an unpopular Supreme Court case by providing that the statute of limitations for equal pay actions resets with every new paycheck.<sup>251</sup> It accomplishes this result by amending Title VII, the ADEA, the ADA, and the Rehabilitation Act of 1973.<sup>252</sup> Despite its compensation provision, GINA is notably absent from the list of amended laws. Perhaps the omission was a simple oversight or a technicality because GINA was not yet in effect. However, after thirteen long years in Congress, it seems hard to believe that GINA would so quickly slip everyone's minds. Alternatively, GINA's absence could mean that the new law is not on equal footing with its predecessors. If so, perhaps the research justification was Congress's singular aim. Only time will tell whether Congress is now truly open to enacting preemptive legislation or whether GINA was just a necessary legal anomaly intended to further science.

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250. Lilly Ledbetter Fair Pay Act of 2009, Pub. L. No. 111-2, 123 Stat. 5 (2009).

251. *Id.*

252. *Id.*