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GINA: A GENETIC INFORMATION NONDISCRIMINATION SOLUTION IN SEARCH OF A PROBLEM

Patricia Alten[*]

ABSTRACT

Genetic discrimination is unfair to workers and their families. It is unjustified—among other reasons, because it involves little more than medical speculation. A genetic predisposition toward cancer or heart disease does not mean the condition will develop. To address the potential use of genetic information by employers to discriminate against employees, Congress enacted the Genetic Information Nondiscrimination Act of 2008 (GINA). This Note proposes the need for modifications to GINA before it is effective in late 2009. In its current state, the provisions relating to employers are overly broad and could catch many employers in unknowing violations. Although GINA prohibits employment discrimination, it does not cover all of America's workers and may be inherently unfair when applied to those it does cover.

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[*] J.D. expected May 2009, University of Florida Levin College of Law; B.A., University of South Florida. This Note is dedicated to my wonderful husband, Larry Cangro, who gave me the courage to embark on a new career path, cheered my successes, provided me with hope when I was discouraged, reminded me that I need to sleep once in awhile, and helped me make my dreams come true. I also want to thank the many people who made this journey possible: my parents, Barbara & Joe Phillips, my son, Nick, and especially my daughter, Amanda, who once put on her facebook page that I was her role model; my friends and co-workers in Tampa who have stood by my side through many events in my life; and the many friends I've acquired during my three years in law school who have inspired me.

I. INTRODUCTION

"You're fired."

Terri Seargent was stunned to hear she was losing her job five days before Christmas.[1] It had only been a month since her supervisor had given her an outstanding performance review, along with her third raise in three years.[2] She had been a rising star at the company when she was abruptly told that her "services were no longer needed."[3]

Puzzled and angry, Terri wondered what motivated her sudden dismissal. Terri speculated that perhaps her recently diagnosed genetic disorder was the cause of her termination.[4] Earlier in the spring, Terri's allergy-like symptoms caused her doctor to suspect she suffered from Alpha-1 Antitrypsin Deficiency,[5] the same hereditary lung disorder that had taken her brother's life.[6] Her doctor suggested augmentation therapy, an expensive treatment.[7]

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[1] Dep't of Health & Human Servs., Nat'l Human Research Prots. Advisory Comm. (NHRPAC) Meeting 1, 295 (Apr. 9, 2001) [hereinafter NHRPAC Meeting] (testimony of Terri Seargent).

[2] *Id.* at 294–95 (testimony of Terri Seargent).

[3] *See id.* at 295 (testimony of Terri Seargent).

[4] *Id.* at 295–96 (testimony of Terri Seargent).

[5] Alpha-1 Antitrypsin Deficiency is a hereditary condition that predisposes affected individuals to liver and lung disease. *See* AlphaNet, FAQs, http://www.alphanet.org/faqs/?c=01-FAQs-about-Alpha-1-Antitrypsin-Deficiency (last visited Feb. 17, 2009). Although Alpha-1 Antitrypsin Deficiency is generally thought of as an extremely rare condition, it is actually one of the most common and serious genetic conditions passed through heredity. *See* AlphaNet Big Fat Reference Guide, *Alpha-1 Antitrypsin Deficiency: What the Heck Is It Anyway?*, http://www.alphanetbfrg.org/BFRG.aspx?ID=1142 (last visited Feb. 17, 2009).

[6] NHRPAC Meeting, *supra* note 1 at 294 (testimony of Terri Seargent).

[7] Augmentation therapy products are made from plasma donation. Augmentation therapy infusions reduce lung function decline in Alpha-1 patients, "and, therefore, improve the long-term quality of life and even the lifespan of individuals with Alpha-1." *See* AlphaNet Big Fat Reference Guide, *My AlphaNet*, http://www.alphanetbfrg.org/AskMedical.aspx (last visited Feb. 17, 2009). Fortunately, Terri learned of her condition early enough to start treatment which would alleviate her symptoms and allow her to "continue to live a productive life." NHRPAC Meeting, *supra* note 1 at 294 (testimony of Terri Seargent).

"[The augumentation therapy] was a way to keep from dying," she later testified to the Department of Health & Human Services.[8] Terri added, "[t]hat decision cost me my job[,] and my family our middle-class lifestyle."[9]

Although genetic discrimination is not a new concept in the United States,[10] dramatic advances in genetics research have far outpaced lawmakers' ability to address its social, ethical, and legal implications.[11] The existing patchwork of federal laws and inconsistent state laws left some individuals without protection. Without a federal law guaranteeing privacy of genetic health information employers and health insurers could use the results of genetic tests to discriminate against employees who might become costly health risks.[12] Fueled by growing public concern,[13] anecdotal stories of genetic discrimination such as Terri's, and urged by a lobby of research scientists unable to find willing subjects, Congress began

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[8] NHRPAC Meeting, *supra* note 1 at 294 (testimony of Terri Seargent). The genetic test provided her with an option her brother never had, and may have even saved her life. *See id.* (testimony of Terri Seargent).

[9] *Id.* (testimony of Terri Seargent).

[10] Some of the most famous words in America's history on genetic discrimination are found in a Supreme Court opinion upholding the eugenic sterilization of eighteen-year-old mentally-handicapped Carrie Buck in *Buck v. Bell*, 274 U.S. 200, 205, 208 (1927). Justice Holmes stated: "It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind . . . . Three generations of imbeciles are enough." *Id.* at 207.

[11] *See generally* NAT'L INSTS. OF HEALTH, U.S. DEP'T OF HEALTH & HUMAN SERVS., HUMAN GENOME PROJECT: FACT SHEET 1, *available at* http://www.nih.gov/about/researchresultsforthepublic/HumanGenomeProject.pdf (stating the project "supported an Ethical, Legal and Social Implications research program to address the many complex issues that might arise from this science"). Researchers today can locate a gene suspected of causing a disease in a matter of days. *Id.* Over 1,000 genetic tests are currently available, and within a few years researchers expect to find genetic factors for heart disease and mental illness as well. *Id.* at 1–2. Some of the issues facing genetic researchers include protecting the privacy of individual genetic information, protecting individuals from discrimination in health insurance and in the workplace, the ethical conflicts between a physician's duty to his patient or duty to warn the family members of a disease they may contract but has not manifested, and the question of whether patients should share in the royalties for research successes. Nat'l Human Genome Inst., Ethical, Legal and Social Implications (ELSI) of Genetic Knowledge, multimedia video and ELSI Vignettes, http://www.genome.gov/25019880 (last visited Feb. 17, 2009).

[12] *See, e.g.*, *Genetic Discrimination: EEOC's First Genetic Testing Challenge Settled for $2.2 Million, Parties Announce*, 90 DAILY LAB. REP. (BNA, Arlington, Va.), May 9, 2002, at A–1.

[13] *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 9–11 (Sept.—Nov. 2004), *available at* http://oba.od.nih.gov/oba/sacghs/reports/Public_Perspectives_GenDiscrim.pdf [hereinafter PUBLIC PERSPECTIVES] (testimony of Rebecca L. Fisher) (describing Fisher's fears that her daughter will be required someday to take a genetic test revealing that she carries the BRCA-1 genetic marker for breast cancer that could result in the loss or denial of either or both employment and health insurance).

discussions of proposed federal bills protecting workers against misuse of genetic data by employers and insurers in 1995.

Finally, in May 2008, President George W. Bush signed the Genetic Information Nondiscrimination Act of 2008 (GINA) into law.[14] Applauded as the first civil rights law of the twenty-first century,[15] and, arguably, the first major civil rights act to protect workers in nearly two decades since the Americans with Disabilities Act of 1990 (ADA) was enacted,[16] GINA appears to be a victory in the battle for individual worker rights. GINA prohibits insurance companies and employers from requiring genetic information from individuals[17] or from discriminating on the basis of genetics.[18] But a closer reading of the law raises questions: Will GINA really protect workers? Or, will it force the situation into an unwieldy framework, "a bit like a mean stepsister trying to push her big foot into one of Cinderella's tiny glass slippers[?]"[19]

This Note discusses how GINA does not benefit workers or employers; protection is erratic at best, unevenly applied, and limited in scope. Part II of this Note addresses genetic testing, consumer fears about loss of health insurance, and the need for federal protection against genetic discrimination. Part III analyzes GINA's interaction with other federal laws protecting workers, and the protections GINA itself will offer workers. Part IV describes the impact on employers and makes recommendations for insuring compliance. Part V proposes a framework for plaintiffs seeking remedies and relief under GINA and outlines the reasons that GINA fails to protect workers.

II. BACKGROUND AND THE NEED FOR GINA

"Humanity's newly acquired ability to map and understand its own genetic traits" is a discovery that has "transform[ed] both science and society."[20] When the Human Genome Project began in 1990,[21] optimism

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[14] Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (to be codified as amended in scattered sections of 26, 29, 42 U.S.C.).

[15] *See* Press Release, Senators Edward M. Kennedy, Mike Enzi, & Olympia Snowe, Kennedy, Enzi, Snowe Celebrate Passage of Genetic Information Nondiscrimination Act (Apr. 24, 2008), *available at* http://kennedy.senate.gov/newsroom/press_release.cfm?id=478F718E-C199-4E4F-9105-23442FA86B71.

[16] Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (codified as amended in scattered sections of 42, 47 U.S.C.).

[17] 29 U.S.C.A. § 1182(c)(1) (West 2008).

[18] *Id.* § 1182(b).

[19] Dewitt v. Proctor Hosp., 517 F.3d 944, 948 (7th Cir. 2008) (describing the difficulty of trying to fit genetic discrimination claims under the ADA).

[20] S. REP. NO. 110-48, at 5 (2007).

[21] NAT'L INSTS. OF HEALTH, U.S. DEP'T OF HEALTH & HUMAN SERVS., HUMAN GENOME PROJECT: FACT SHEET, *supra* note 11, at 1. The Human Genome Project was a joint effort by the

was boundless—researchers would have the means to look for cures to diseases, doctors would provide better medical advice, and patients, armed with advanced knowledge of a predisposition for a health problem, would seek preventative care.[22] By 2003, when the exact sequence of the human genome was decoded,[23] some individuals had already experienced what Congress would recognize as a danger—a person's very intimate genetic code being "used for harmful purposes . . . . [For instance, an] employer might use information about an employee's genetic profile to deny employment to an individual who is healthy and able to do the job."[24]

Genetic research into relationships between genetic markers[25] and "non-medical conditions, such as intelligence and personality traits" present an even greater challenge to lawmakers as researchers continue to explore the vast possibilities unveiled by the Human Genome Project.[26] Genetic tests are available for over 1,000 different markers for diseases and range in price from $200 to $3,000.[27] Genetic data reveals very personal details about an individual, including intimate facts the individual did not already know—from personal identification to biological relationships to health factors.[28] The data revealed is not limited to the individual who is tested; test results disclose intimate data and "important biological facts about . . . parents, siblings, and children."[29] Public concerns about misinterpretations of diagnoses, lack of available options until and unless the disease actually manifests, and personal stories of discrimination by insurers and employers, led Congress to begin deliberations on federal protections for citizens.[30]

National Institutes of Health (NIH), the Department of Energy (DOE), and international partners to sequence all three billion letters in the human DNA. *Id.* The goal of the project was to provide researchers with the ability to find genetic markers to diseases in human DNA, thus enabling them to develop cures, earlier diagnoses, and innovative prevention tactics. *Id.*

[22] *See* S. REP. NO. 110-48, at 5.

[23] NAT'L INSTS. OF HEALTH, U.S. DEP'T OF HEALTH & HUMAN SERVS., HUMAN GENOME PROJECT: FACT SHEET, *supra* note 11, at 1.

[24] S. REP. NO. 110-48, at 5–6.

[25] A genetic marker is a gene which has an easily identifiable characteristic and can be used to mark "cell nuclei or chromosomes so that they can easily be isolated or identified from other nuclei or chromosomes later." Mondofacto Online Medical Dictionary, http://www.mondofacto.com/facts/dictionary?query=genetic+marker&action=look+it+up (last visited Jan. 25, 2009).

[26] *See* NAT'L INSTS. OF HEALTH, U.S. DEP'T OF HEALTH & HUMAN SERVS., HUMAN GENOME PROJECT: FACT SHEET, *supra* note 11, at 2.

[27] Human Genome Project Information, Gene Testing, http://www.ornl.gov/sci/techresources/Human_Genome/medicine/genetest.shtml (last visited Feb. 17, 2009).

[28] Lawrence O. Gostin, *Health Information Privacy*, 80 CORNELL L. REV. 451, 491 (1995).

[29] *Id.*

[30] *See* S. REP. NO. 110-48, at 1, 6–8.

When Terri was fired, she lost more than just a nice income, she also lost the health insurance that helped pay for the very expensive treatments she needed to keep her alive.[31] Once she was labeled with the Alpha-1 gene, she became uninsurable, and her family's savings were quickly depleted in order to pay for her treatments.[32] As Terri's story demonstrates, genetic discrimination directly impacts an individual's employment opportunities, as well as her ability to obtain health insurance, disability insurance, and life insurance.

For most Americans, "the ticket to health care services of any kind or quality" is through health insurance coverage.[33] Most Americans rely on their jobs for health insurance.[34] Without a job or health insurance benefits, treatment and medication for a disease resulting from a genetic disorder is probably unaffordable for the average American. Genetic discrimination not only affects the ability of those afflicted with a genetic disorder to access health care, it also has a dramatic impact on the probability that future generations will be denied health care and employment if they are labeled with defective genes or labeled as carriers.

Phil Hardt and his family know all too well the impact of genetic labeling.[35] Unlike Terri, Phil managed to avoid losing his job despite diagnoses of hemophilia B and Huntington's Disease.[36] However, hiding his afflictions from his supervisor was only the beginning of his battle with genetic discrimination which eventually extended to three generations of his family.[37] For almost four decades, Phil, his children, and his grandchildren were denied all types of insurance due to their genetic

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[31] *See* NHRPAC Meeting, *supra* note 1, at 296 (testimony of Terri Seargeant).

[32] *Id.* at 295–97 (testimony of Terri Seargeant).

[33] Robert H. Jerry, II, *Life, Health, and Disability Insurance: Understanding the Relationships*, 35 J.L. MED. & ETHICS 80, 82 (Supp. 2007).

[34] *See* HENRY J. KAISER FAMILY FOUND., *Summary of Findings*, EMPLOYER HEALTH BENEFITS 2008 ANN. SURV. 1 (2008), *available at* http://ehbs.kff.org/pdf/7791.pdf [hereinafter EMPLOYER HEALTH BENEFITS].

[35] *See* PUBLIC PERSPECTIVES, *supra* note 13, at 23–36 (testimony of Phil Hardt).

[36] *Id.* at 23 (testimony of Phil Hardt). For more information on Hemophilia B, see generally Nat'l Hemophilia Found., Hemophilia B (Factor IX), http://www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=181&contentid=46 (last visited Feb. 26, 2009). Hemophilia B is a bleeding disorder that occurs in one in 25,000 male births. *Id.* Hemophilia is usually inherited, but approximately 30% of the time it results when there is no familial history. *Id.* For more information about Huntington's Disease, see generally Huntington's Disease Soc'y of Am., What is Huntington's Disease (HD)?, http://www.hdsa.org/about/our-mission/what-is-hd.html (last visited Feb. 17, 2009) (describing Huntington's Disease (HD) as "a devastating, hereditary, degenerative brain disorder for which there is, at present, no effective treatment or cure"). Huntington's Disease is a degenerative disease that "slowly diminishes the affected individual's ability to walk, think, talk and reason." *Id.*

[37] PUBLIC PERSPECTIVES, *supra* note 13, at 23–24 (testimony of Phil Hardt).

diagnoses.[38] Even before his diagnosis of Huntington's, insurers denied him credit insurance.[39] After his divorce, he was denied long term-care insurance when he most needed someone to care for him.[40] His daughter was denied life insurance and mortgage life insurance because of Phil's diagnosis and was told by the insurance companies that she could not purchase coverage unless she provided negative test results for the Huntington's gene.[41]

Stories like Phil's and Terri's reached lawmakers. To learn about the public's fears of discriminatory treatment, Congress conducted public hearings about genetic testing.[42] Individuals wrote, emailed, faxed, and testified about experiences with discrimination in health insurance and many voiced genuine concern that employers might discriminate in the interest of cutting health care costs.[43]

Congress determined that existing laws did not adequately protect the public from potential genetic discrimination.[44] For example, while an insurer could not charge one individual in a group a higher premium than the rest of the group based on genetic information,[45] the insurer was free to establish premiums for the entire group based on genetic information of

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[38] *Id.* at 24 (testimony of Phil Hardt).

[39] *Id.* (testimony of Phil Hardt).

[40] *Id.* at 24, 33–36 (testimony of Phil Hardt).

[41] *Id.* at 24, 29–32 (testimony of Phil Hardt). Because of the blatant genetic discrimination that Phil Hardt and his eldest daughter experienced when trying to purchase insurance, Phil worked with a Tucson geneticist and the Arizona chapter of the Huntington's Disease Society of America to establish an anonymous testing procedure for his other children. *Id.* at 24 (testimony of Phil Hardt). He has also helped others in his support group to get similar testing. *Id.* at 24, 27 (testimony of Phil Hardt). Under the testing, "[t]he person uses a bogus name, address, phone and social security number and pays cash to find out anonymously if they have HD . . . ." *Id.* at 27 (testimony of Phil Hardt). Although the subterfuge is expensive, the results don't go into the patient's medical record or medical database. *Id.* at 26 (testimony of Phil Hardt). Then, if a person finds out they have the gene for Huntington's, "[she] can get all of the necessary insurances before they become symptomatic." *Id.* at 27 (testimony of Phil Hardt).

[42] *See generally* PUBLIC PERSPECTIVES, *supra* note 13 (providing the testimonies by those having faced alleged genetic discrimination given to the Secretary's Advisory Committee on Genetics, Health, and Society). For example, Tonia Phillips, who has the genetic marker for breast and ovarian cancer (BRAC-1), was asked by her boss to switch to her husband's insurance. *Id.* at 14 (written comment of Tonia Phillips). In another situation, Paula Funk's doctors advised her against genetic testing for BRAC-1, despite a strong familial history for breast cancer. She tested anyway, hoping that if she paid directly her insurer would not have access to her genetic tests. When she tested positive and needed to justify expensive screening tests, the insurer had access to the information and her insurance rates increased $100 a month. *Id.* at 16-19 (written comment of Paula Funk).

[43] See generally PUBLIC PERSPECTIVES, *supra* note 13.

[44] *See* S. REP. NO. 110-48, at 10–15.

[45] *Id.* at 9–10.

one individual.[46] The health insurance industry argued that for accurate risk assessment in small- to mid-sized groups, insurers must be permitted to rate policies based on the highest risk individuals.[47] Congress also criticized the Health Insurance Portability and Accountability Act (HIPAA)[48] because it applied only to insurance companies writing group health policies and exempted insurance companies writing policies for individuals.[49]

In light of the limitations of existing laws and testimony before various committees of the House and Senate, the Senate Committee on Health Education, Labor, and Pensions concluded in its report that new federal legislation was needed to protect individuals from potential genetic discrimination in health insurance and employment.[50]

III. THE LAWS GOVERNING GENETIC DISCRIMINATION

A. *Federal Law Predating GINA*

Prior to the enactment of GINA, three federal laws and a presidential order provided limited federal protection against genetic discrimination. Title VII of the Civil Rights Act of 1964 (Title VII),[51] provided "no obvious protection against genetic discrimination," although an employee might find indirect protection if an employer used genetic information to discriminate on the basis of "race, color, religion, sex, or national origin."[52]

The primary federal laws protecting against genetic discrimination are based on health rather than visible factors of discrimination found under Title VII. The ADA does not specifically discuss genetic discrimination but the EEOC has stated that employees could find protection under one of the ADA's three prongs.[53] For individuals who have not manifested

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[46] *Id.* at 10.

[47] *Genetic Non-Discrimination: Implications for Employer Provided Health Care Plans: Hearing Before the Subcomm. on Employer-Employee Relations of the H. Comm. on Education and the Workforce*, 107th Cong. 33–37 (2001) (statement of Janet Trautwein, Director of Federal Policy Analysis and State Government Affairs, National Association of Health Underwriters).

[48] Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (codified as amended in scattered sections of 18, 26, 29, 42 U.S.C.).

[49] S. REP. NO. 110-48, at 10 (2007).

[50] *Id.* at 10, 13–15.

[51] 42 U.S.C. §§ 2000e–17 (2006). Exec. Order No. 13,145, 65 Fed. Reg. 6,877 (Feb. 8, 2000).

[52] S. REP. NO. 110-48, at 11 (2007).

[53] Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (codified as amended in scattered sections of 42, 47 U.S.C.). The term "disability" with respect to an individual is defined with three prongs as: "(A) a physical or mental impairment that substantially

symptoms, the prong would likely be the "regarded as" prong which protects an employee when an employer mistakenly believes that an employee has a substantially limiting physical disability or mistakenly believes the employee's disability limits activities more than it really does.[54] Congress's intent in crafting the "regarded as" prong was to protect individuals who might be denied employment based on "'myths, fears and stereotypes associated with disabilities."[55] Terri's claim of discrimination against her employer was filed under this prong of the ADA.[56]

Terri's firing arose as a result of her doctor's disclosure of her confidential medical information to her employer.[57] Doctor-patient confidentiality, once sacred, has become a confusing conundrum of laws, acronyms, misunderstandings, and fear of litigation.[58] The advancement of genetic knowledge, in tandem with rapidly-increasing development in technology, poses compelling privacy concerns.[59] HIPAA might have provided Terri with a cause of action against her employer.[60] HIPAA serves dual functions to protect participants of group health plans. One function is protecting the privacy of a patient's confidential medical information by prohibiting covered entities from protected health

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limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment." *See* Nat'l Workrights Inst., The ADA's Definition of "Disability," http://www.workrights.org/issue_genetic/gd_ada.html (last visited Feb. 17, 2009). *See also* Tresa Baldas, *Legal Tension Grows Over Genetic Tests: Privacy, Potential Discrimination are Major Concerns*, 28 NAT'L L. J., Oct. 31, 2005, at 1.

[54] *See* Nat'l Workrights Inst., *supra* note 53.

[55] Sutton v. United Air Lines, Inc., 527 U.S. 471, 489–90 (1999) (quoting 29 C.F.R. pt. 1630, App. § 1630.2(*l*) (2008)).

[56] *See* NHRPAC Meeting, s*upra* note 1, at 297 (testimony of Terri Seargent). Terri's claim was settled by the EEOC before suit. *Id.* (testimony of Terri Seargent). Although Terri testified that she was considered under the second prong, "regarded as being disabled" is generally considered the third prong of the ADA.

[57] NHRPAC Meeting, s*upra* note 1, at 295 (testimony of Terri Seargent).

[58] *See* JUNE M. SULLIVAN, HIPAA: A PRACTICAL GUIDE TO THE PRIVACY AND SECURITY OF HEALTH DATA 2 (2004).

[59] *See* Gostin, s*upra* note 28, at 491–92.

[60] HIPAA's privacy protection is limited. S. REP. NO. 110-48, at 9–10 (2007). HIPAA does not apply to medical providers who do not submit forms in electronic format, nor does it apply to group health plans with fewer than fifty participants, employer self-insured plans that are administered by the employer, or health insurers writing individual policies. 45 C.F.R. § 160.103 (2006); *see also* SULLIVAN, *supra* note 58, at 4. Although fines and criminal penalties are established for disclosing protected information, "HIPAA does not require [covered] entities to notify individuals after unauthorized or wrongful disclosure of individually identifiable health information" has occurred. Brandon Faulkner, Note, *Hacking into Data Breach Notification Laws*, 59 FLA. L. REV. 1097, 1116 (2007). In fact, Congress may have omitted the notification requirement because they may have "viewed the issue as a personal information privacy matter, rather than an identity theft issue." *Id.*

information without a patient's authorization.[61] HIPAA also assures the portability of health insurance coverage, enabling individuals to change health carriers after a change of job without denial or increased rates based on pre-existing conditions.[62] It is in this area that HIPAA provides "some protection against discriminatory practices in health insurance based on an individual's genetic information."[63]

B. *And Along Comes GINA*

GINA, which will be effective in late 2009, covers two broad areas of genetic discrimination: health insurance coverage and employment.[64] Health insurance and employment are frequently tied together because most Americans rely on their employers for health insurance. GINA's Title II prohibits employment discrimination[65] by employers,[66] labor unions,[67] employment agencies,[68] and training programs.[69] GINA prohibits discrimination in hiring, discharge, or with respect to compensation, terms, or privileges of employment based on genetic information.[70] Further, it is unlawful for employers to acquire genetic information about an employee

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[61] 45 C.F.R. pts. 160, 164 (2002).

[62] S. REP. NO. 110-48, at 9–10.

[63] *Id.* at 9.

[64] This Note discusses only Title II of GINA. Title I of GINA prohibits health insurers from underwriting policies or adjusting premiums in a health insurance plan based on genetic test results of any individual or family member of an individual covered in a plan. Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (to be codified as amended in scattered sections of 26, 29, 42 U.S.C.). Insurers cannot require an individual or a family member to undergo a genetic test. Further, insurers cannot request, require, or purchase information about an individual for underwriting purposes prior to enrollment. *Id.* §§ 101–106 (to be codified as amended in scattered sections of 26, 29, 42 U.S.C.). Members of the health insurance industry have suggested that "section 101 . . . could limit consumer access to life-saving treatments because it prohibits health insurance plans from 'requesting or requiring' an individual . . . to undergo a genetic test . . . even when it is needed to determine the appropriate course of treatment and evaluate the patient's eligibility for coverage." *Hearing on Genetic Non-Discrimination: Hearing Before the Subcomm. on Health of the H. Comm. on Ways and Means*, 110th Cong. (2007) (statement of William D. Corwin, M.D., Medical Director, Clinical Policy, Harvard Pilgrim Health Care on behalf of America's Health Insurance Plans). Because of rapid and unforeseen advances in medicine, insurers urged Congress to consider that the future might hold many legitimate circumstances where health insurers would need to request genetic testing for the benefit of the patient and that the language of GINA is too limiting to permit insurers to request these tests. *Id.*

[65] *Id.* §§ 201–213 (to be codified as amended in scattered sections of 42 U.S.C.).

[66] *Id.* § 201(2)(B) (to be codified at 42 U.S.C. § 2000ff(2)(B)).

[67] *Id.* § 201(2)(C) (to be codified at 42 U.S.C. § 2000ff(2)(C)).

[68] *Id.*

[69] *Id.* § 205 (to be codified at 42 U.S.C. § 2000ff-4(a)). Throughout the balance of this Note, the term "employers" will refer to any of these organizations.

[70] *Id.* § 202(a)(1) (to be codified at 42 U.S.C. § 2000ff-1(a)(1)).

or an employee's family member, except under certain conditions.[71] Employers who acquire or possess confidential genetic information about an employee are required to treat the genetic information as part of a confidential medical record and maintain it separately.[72] Treating confidential information in the same manner as confidential ADA medical records ensures that employers are in compliance.[73] Employers may not disclose genetic information, except to the employee at the employee's written request or in certain other limited circumstances.[74]

IV. GINA'S IMPACT ON THE WORKPLACE

A. *Employer Concerns*

Employers argued vehemently against GINA.[75] Its remedial measures and punitive clauses leave employers vulnerable to stiff fines and lawsuits from employees. Employers were concerned that as new genetic markers are discovered, the broad language in previous versions of GINA might result in employees demanding that employers provide health coverage for every possible genetic disorder.[76] GINA does not limit the use, acquisition, possession, or disclosure of genetic information to asymptomatic or predictive information, therefore, employers could easily find themselves in violation of collecting information from applicants or employees about family members. Another problem facing employers is that the statute does not address what employers are to do with any non-medical personnel records containing familial medical data.

Conflicts with existing state and federal laws could prove to be another potential pitfall for employers. Currently, thirty-four states and the District of Columbia have existing laws prohibiting genetic discrimination and several states have enacted legislation prohibiting the disclosure of genetic

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[71] *See id.* § 202(b) (to be codified at 42 U.S.C. § 2000ff-1(b)). Exceptions include: inadvertence; written consent of the employee; disclosure by a genetic counselor providing services to the employee; compliance with the Family and Medical Leave Act of 1993; purchase of documents that are commercially and publicly available; biological effects of toxic substances in the workplace with additional conditions; and if the employer conducts DNA analysis for law enforcement or other purposes, and then only to exclude employees from sample contamination. *Id.*

[72] *Id.* § 206(a) (to be codified at 42 U.S.C. § 2000ff-5(a)).

[73] *Id.*

[74] *Id.* § 206(b) (to be codified at 42 U.S.C. § 2000ff-5(b)).

[75] *See Protecting Workers from Genetic Discrimination: Hearing Before the Subcomm. on Health, Employment, Labor, and Pensions of the H. Comm. on Education and Labor*, 110th Cong. 49 (2007) (statement of Burton J. Fishman, Partner, Fortney Scott, LLC, Genetic Information Nondiscrimination in Employment (GINE) Coalition).

[76] GINA's § 209(a)(7) should relieve some of employers' concerns. Genetic Information Nondiscrimination Act of 2008, § 209(a)(7) (to be codified as amended in 29 U.S.C. § 1182(d)(1)).

information without the owner's consent.[77] Employers are concerned that Congress did not adequately consider potential conflicts with existing laws.

A major concern to both employers and insurers is GINA's definition of "genetic test" as "an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes."[78] In congressional hearings and reports submitted to Congress, employers and representatives of the health insurance industry objected to the definition in the proposed versions of the law as overly broad and vague.[79] The health insurance industry recommended the definition of "genetic test" be limited to predictive testing performed on asymptomatic or undiagnosed individuals for the purposes of assessing the risk of future disease.[80]

Employer groups and insurance industry representatives argued that the "current definition of genetic test[ing] . . . could serve to prohibit items like cholesterol tests, performed to detect symptoms, clinical signs or a diagnosis of disease. It could also hinder current and advancing methods of detecting cancer."[81] The definition of "genetic test" could also increase medical liability for health care providers who may not meet an arbitrary standard of care.[82] However, Congress did not listen to the scientists and

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[77] Bill Leonard, *The Stealth Statute*, HR MAGAZINE 47, 48 (Dec. 2008). *See, e.g.*, ALASKA STAT. §§ 18.13.010-18.13,100 (permitting a private cause of action for actual damages along with statutory damages of either $5,000 or $100,000 (§ 18.13.020)); CAL. INS. CODE § 10149.1; NEV. CODE ANN. §§ 629.101–629.201.

[78] *Id.* § 101(d)(7)(A) (to be codified as amended in 29 U.S.C. § 1191b(d)(7)(A)).

[79] Statement from Janet Stokes Trautwein, Executive Vice President and CEO, National Association of Health Underwriters, for the House Committee on Education and Labor Regarding H.R. 493: The Genetic Information Nondiscrimination Act of 2007 (Feb. 14, 2007), *available at* http://www.nahu.org/legislative/genetic/GeneticsEdLaborStatement.pdf [hereinafter Trautwein 2007 Written Statement]. The statement is extremely broad, even with the exceptions that a genetic test is not "an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes," nor is it "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." *Id.*

[80] *Id.* The National Association of Health Underwriters (NAHU) proposed the following language to define genetic test: "analysis of human DNA . . . associated with an increased statistical risk of development of a disease or disorder, and the analysis is performed for the purposes of predicting risk of disease or disorders in asymptomatic individuals." *Id.* The NAHU also proposed that the definition contain the following exception: "[that] [s]uch term does not include physical and chemical tests, such as blood or urine analyses of the individual, including cholesterol tests and physical exams of the individual, or a test to determine the illegal use of drugs." *Id.*

[81] *Id.*

[82] *Id.* Members of the health insurance industry have suggested that some sections of GINA "could limit consumer access to life-saving treatments because it prohibits health insurance plans from 'requesting or requiring' an individual . . . to undergo a genetic test . . . even when it is needed to determine the appropriate course of treatment and evaluate the patient's eligibility for coverage."

adopted the ambiguous language of the proposed law. When plaintiff lawyers look at the broad definition in conjunction with the other benefits offered by the remedies outlined below, an onslaught of litigation from employees could result.

B. *A Roadmap for Employer Compliance*

There is no doubt that GINA will have a significant impact on most workplaces. To ensure that human resources departments are in compliance when GINA becomes effective, employers should prepare in advance. Proper training on the important aspects of the new law for administrative staff in charge of hiring and benefits management is essential.

Most employers offering health insurance to employees are likely to possess some family history information in personnel records. Employers should review personnel files and employee records and purge all information that could be construed as genetic information, including medical information and family histories. Performance reviews, written reprimands, and file memos should be carefully reviewed for possible mentions of a familial health problem.

To illustrate how a potential problem could arise, suppose employee *A* took bereavement leave to attend the funeral of a relative two years ago. As part of the employer policy, *A* provided a copy of the death certificate in order to be paid for bereavement time. The employer retained the death certificate with the payroll records, along with the supervisor's memo approving the leave. If the relative falls within the four degrees of generations described in the statute and the cause of death listed is one that is known to have genetic markers, or is discovered in the future to have genetic markers, then *A* may have a cause of action if he is terminated.

A second illustration demonstrates how innocent comments in personnel files by supervisors or employees could pose a potential problem under GINA. Suppose last year employee *B*'s supervisor reprimanded *B*, an employee with mediocre performance, about a recent problem with tardiness. In her comments in the file memo, the supervisor noted that *B*'s reason was because *B*'s mother's work schedule had changed, so *B* had become responsible for giving her diabetic brother his shots in the morning before taking him to school. The supervisor counseled *B* and allowed her

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Hearing on Genetic Non-Discrimination: Hearing Before the Subcomm. on Health of the H. Comm. on Ways and Means, 110th Cong. (2007) (statement of William D. Corwin, M.D., Medical Director, Clinical Policy, Harvard Pilgrim Health Care on behalf of America's Health Insurance Plans). Because of rapid and unforeseen advances in medicine, insurers urged Congress to consider that the future might hold many legitimate circumstances where health insurers would need to request genetic testing for the benefit of the patient and that the language of GINA is too limiting to permit insurers to request these tests. *Id.*

to adjust her work hours to accommodate the additional family responsibilities. In this reference, genetic markers for diabetes have been disclosed, thus *B* may have a cause of action.

Employers with multiple locations will need to understand what impact GINA will have on the various state laws and federal statutes already in effect.[83] There is an exception in GINA for obtaining information for leave under the Family Medical Leave Act (FMLA). However, employers must be careful not to confuse gathering information to support FMLA leave with obtaining it for employer-sponsored leave, which would be a violation of GINA. Similarly, employers should carefully review their practices of gathering information for health insurance and wellness programs to insure employer procedures are in compliance.[84]

Employers who are also administrators of the company's health care plan face an inherent conflict of interest because of their dual roles. Those employers should be cautious about denying benefits or terminating plans "unless the benefit plan gives the administrator or fiduciary discretionary authority to determine eligibility for benefits or to construe the terms of the plan."[85] Employers and their human resources professionals should tread carefully with this new law. GINA's impact will be felt by many employers that inadvertently violate its provisions and incur penalties.

V. GINA'S IMPACT ON WORKERS

A. *A Proposed Framework for Causes of Action*

The EEOC and Department of Labor are in the process of drafting regulations for the enforcement of GINA.[86] Section 207 of GINA provides remedies for employees who allege unlawful employment practices of genetic discrimination.[87] Nonfederal employees bringing charges of genetic discrimination against an employer would file a claim with the EEOC within 180 days of the date of the discriminatory act.[88] The date of the

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[83] Leonard, *supra* note 77, at 48.

[84] Leonard, *supra* note 77, at 49.

[85] Firestone Tire & Rubber Co. v. Bruch, 489 U.S. 101, 115 (1989) (finding the de novo standard of review applies unless the plan has given the fiduciary authority to set the terms of the plan, and that any possible or actual conflict of interest will be "weighed as a 'facto[r] in determining whether there [has been] an abuse of discretion'" (quoting RESTATEMENT (SECOND) OF TRUSTS § 187 cmt. d (1959)) (first alteration in original)).

[86] Leonard, *supra* note 77, at 49.

[87] Genetic Information Nondiscrimination Act of 2008, § 207 (to be codified at 42 U.S.C. § 2000ff-6).

[88] 42 U.S.C. § 2000e-5(e)(1) (2006). The deadline is 300 days if an applicable state or local law also prohibits the discriminatory act. *Id.*; *see* U.S. E.E.O.C., Filing a Charge of Employment Discrimination: What are the Time Limits for Filing a Charge of Discrimination?, http://www.eeoc.gov/charge/overview_charge_filing.html (last visited Feb. 17, 2009).

discriminatory act is generally held to be the date an employee is made aware of a decision involving the employee, not when the decision takes effect.[89] The EEOC will perform an investigation, mediate, and attempt conciliation.[90] If no conciliation is possible, it will issue a "right-to-sue" letter, giving plaintiff the private right to sue.[91] Plaintiffs may then hire private counsel, who become, in effect, private attorneys general.[92]

The framework of a genetic discrimination case against an employer could vary greatly depending on the nature of the discrimination alleged and the basis of the employer's knowledge about plaintiff's genetics. In general, a plaintiff will make either a direct or an indirect discrimination case.[93] In the direct method, plaintiff would present all circumstantial and non-circumstantial evidence.[94] Defendant would do the same.[95] If a reasonable jury could find discrimination, then the case will survive summary judgment.[96]

In *McDonnell Douglas Corp. v. Green*,[97] the Supreme Court established a burden-shifting test for bringing indirect Title VII discrimination cases.[98] Under the *McDonnell Douglas* framework, plaintiff bears the initial burden of presenting a prima facie case that he or she (1) is a member of the group protected by the law; (2) was discriminated against in the course of employment; (3) is qualified, but was rejected; and (4) the position remained open and the employer continued to seek applicants from others with qualifications similar to plaintiff's.[99] Then, the burden of proof shifts to the defendant-employer to articulate a legitimate, nondiscriminatory reason for its adverse employment action.[100] Plaintiff must then meet the final burden of proving that the employer's motives were a pretext.[101]

Plaintiff's protected group, under a *McDonnell Douglas* analysis of GINA, would include an employee who: (1) had a genetic test; or (2) has

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[89] *See, e.g.*, Del. State Coll. v. Ricks, 449 U.S. 250, 258–59 (1980) (finding that plaintiff's time period for filing began to toll when he was first notified that he would be denied tenure, not when his contract terminated).

[90] 42 U.S.C. § 2000e-5(b) (2006); *see also* U.S. E.E.O.C., EEOC's Charge Processing Procedures, http://www.eeoc.gov/charge/overview_charge_processing.html (last visited Feb. 17, 2009).

[91] U.S. E.E.O.C., EEOC's Charge Processing Procedures, *supra* note 90.

[92] 42 U.S.C. § 2000e-5(f)(1).

[93] *See, e.g.*, Dewitt v. Proctor Hosp., 517 F.3d 944, 950 (7th Cir. 2008) (Posner, J., concurring).

[94] *Id.*

[95] *Id.*

[96] *Id.*

[97] 411 U.S. 792 (1973).

[98] *Id.* at 801–02.

[99] *Id.* at 802.

[100] *Id.*

[101] *Id.* at 804.

a family member, including a dependent or a first-, second-, third-, or fourth-degree relative[102] who has had a genetic test; or (3) has a family member, including a dependent or first-, second-, third-, or fourth-degree relative, who manifests a disease or disorder.[103] This relative pool is very broad, and there is no requirement in the statute that the disease or disorder manifested by any of the near or distant relatives in the pool is one that has a known genetic marker.[104] Other than the exception noted for inadvertence, the statute is not specific about an employer's knowledge of the employee's family genetic history and its instrumentality in a discrimination claim.[105] For smaller companies or small towns with one or two major employers where supervisors know employees and their families personally, this could be problematic. To mollify employers, § 210 adds another limitation—employers will not violate GINA for using or disclosing "medical information that is not genetic information about a manifested disease [or] disorder . . . that has or may have a genetic basis."[106] But, sources of available genetic fodder still remain wide-open.

It is possible that if a plaintiff claimed discrimination based on a family member's manifested disease or disorder, a court might analogize the analysis to a claim under the association discrimination provision of the ADA. That provision prohibits employers from discriminating against an employee simply because of the employee's association or relationship with a person with a disability.[107] Under the ADA analysis, the employer must know of the relationship and of the other person's illness in order for plaintiff to make a prime facie case.[108] In *Larimer*, the court described the

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[102] First-degree relatives include children and parents; second-degree relatives include grandparents, siblings, and grandchildren; third-degree relatives include uncles, aunts, nieces, nephews, great-grandparents, and great-grandchildren; fourth-degree relatives include first cousins, great-great-grandparents, great-uncles, great-aunts, grandnephews, and grandnieces (i.e., children of nieces and nephews). JOEL C. DOBRIS, STEWART E. STERK & MELANIE B. LESLIE, ESTATES & TRUSTS 69 tbl. (3d ed. 2007).

[103] Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233 §§ 201–202, 122 Stat. 881, 905–07 (to be codified at 42 U.S.C. §§ 2000ff–2000ff-1). In contrast, California's corresponding statute defines inherited genetic characteristics as those that: "may derive from the individual or family member, . . . or that are determined to be associated with a statistically increased risk of development of a disease or disorder, and that are presently not associated with any symptoms of any disease or disorder." CAL. GOV'T CODE § 12926(h)(2)(B) (West 2008).

[104] For an up-to-date status on new diseases with genetic markers, see GeneTests, What's New in *GeneReviews*?, http://www.genetests.org (follow "New in *GeneReviews*" hyperlink) (last visited Feb. 17, 2009).

[105] *See* Genetic Information Nondiscrimination Act of 2008, § 203(b) (to be codified at 42 U.S.C. § 2000ff-2).

[106] *Id.* § 210 (to be codified at 42 U.S.C. § 2000ff-9).

[107] 42 U.S.C. § 12112(b)(4) (2006).

[108] *See, e.g.*, Poveromo-Spring v. Exxon Corp., 968 F. Supp. 219, 227 (D.N.J. 1997) (finding plaintiff's claim—that he was fired after his mother was diagnosed with a brain ailment and had

three types of cases that might arise under association-based discrimination.[109] The first type of case relates to the expense of a disability; for example, when a "spouse has a disability that is costly to the employer because the spouse is covered by the company's health plan."[110] The second category is broken into two subsections of disability by association—one dealing with the employee's homosexual partner, and the other dealing with the employee's blood relative.[111] One example given by the court of this latter subcategory was that "one of the employee's blood relatives has a disabling ailment that has a genetic component and the employee is likely to develop the disability as well."[112] The third category is the employer's fear that the employee will be distracted by caring for a loved one with a disability.[113]

In *Dewitt*, a more recent case, the Seventh Circuit suggested the traditional *McDonnell Douglas* test is an unwieldy framework for deciding an association discrimination case by describing it as "a bit like a mean stepsister trying to push her big foot into one of Cinderella's tiny glass slippers."[114] The court argued the *McDonnell Douglas* framework did not consider the expense factor of association discrimination discussed by the Seventh Circuit in *Larimer*,[115] and found it particularly onerous in *Dewitt*.[116] The court seemed to suggest that the *McDonnell Douglas* framework should be tweaked to permit plaintiff to include circumstantial evidence of the employer's economic motive in plaintiff's prima facie case.[117] A form of employment discrimination based on the expensive employee, or the employee with the expensive dependents, would be consistent with Congress's findings that advances in genetics "give rise to the potential misuse of genetic information to discriminate in health insurance and employment,"[118] and that "employers may come to rely on

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a seizure at the same workplace—was sufficient to support a claim of association-based discrimination for the jury).

[109] Larimer v. IBM Corp., 370 F.3d 698, 700 (7th Cir. 2004).

[110] *Id.*

[111] *Id.*

[112] *Id.*

[113] *Id.*

[114] Dewitt v. Proctor Hosp., 517 F.3d 944, 948 (7th Cir. 2008).

[115] *Larimer*, 370 F.3d at 701; *see* Dewitt, 517 F.3d at 947–48 (describing the difficulty the court experienced in *Larimer* in trying to adapt the *McDonnell Douglas* test to the "expense" category of ADA association discrimination claims).

[116] *Dewitt*, 517 F.3d at 948 (stating that the financial implications of employee's spouse's continued cancer treatments were certainly a factor in her termination).

[117] *See id.* at 951–53 (Posner, J., concurring).

[118] Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, § 2, 122 Stat. 881, 882 (to be codified at 42 U.S.C. § 2000ff n.).

genetic testing to 'weed out' those employees who carry genes associated with diseases."[119]

Adopting an economic doctrine of employment discrimination is unnecessary and could be a dangerous precedent. There are already laws to protect employees from employers trying to withhold benefits.[120] Employers are currently free to purchase insurance with caps of liability; or, for self-insured employers, to cap the liability per employee.[121] Further, a doctrine of economic employment discrimination would lead to an overly broad interpretation of disability. As the Fifth Circuit noted, "[t]o interpret 'discrimination' broadly . . . would clearly conflict with Congress's intent that employers remain free to create, modify and terminate the terms and conditions of employee benefits plans without governmental interference."[122] This would be a bit like forcing the Prince to marry the mean stepsister just because she could force her foot into the tiny shoe.

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[119] S. REP. NO. 110-48, at 6 (2007). A 2004 Medical Testing Survey conducted by the American Management Association indicates that nearly 63% of employers who responded to the survey required employees to submit to some type of medical testing. AM. MGMT. ASS'N, AMA 2004 WORKPLACE TESTING SURVEY: MEDICAL TESTING 1, *available at* http://www.amanet.org/research/pdfs/Medical_testing_ 04.pdf (on file with author). Stories like the public battle between the National Basketball Association (NBA) and star player Eddy Curry have enhanced public concerns about genetic testing. *See* Jim Litke, *Curry at Center of "Fight Far Bigger Than Sports,"* L.A. TIMES, Oct. 2, 2005, at D-2. The NBA made headline news when the Chicago Bulls demanded that its talented center submit to DNA testing for a genetic heart disease. *Id.* Curry refused the invasive test and, after months of conflict that played out in the press, was traded to the Knicks without the test. Michael A. McCann, *The Reckless Pursuit of Dominion: A Situational Analysis of the NBA and Diminishing Player Autonomy*, 8 U. PA. J. LAB. & EMP. L. 819, 849 (2006). As a result of the conflict with Eddy Curry, the NBA now requires mandatory cardiac testing of its athletes. Howard Beck, *The N.B.A. Is the First League to Begin Standardized Cardiac Screening*, N.Y. TIMES, Sept. 17, 2006, at 8-5. While not quite the same level of invasiveness as DNA testing, the mandatory tests still provide the teams with much more information about a player's health and private information than most individuals want to share. *Id.* David Stern, the NBA commissioner, justified player testing as a business investment decision:

> If you're thinking about drafting a player, you do blood [tests], you do X-rays, skeletal, you look for scars, for breaks, for weaknesses, for disease. I don't know what you would be looking for with DNAs [sic], but given the size of the contract and the importance of the draft pick, I think that diagnostic testing that tells you whether you're making a good investment is not a bad idea.

Stern Backs Bulls in DNA Testing of Curry, ESPN.COM, Sept. 30, 2005, http://sports.espn.go.com/nba/news/story?id=2176913 (first alteration in original) (quoting David Stern, NBA Commissioner).

[120] ERISA would likewise protect employees who learn that they or their dependents have a genetic disorder. *See, e.g.*, 29 U.S.C. § 1140 (2006).

[121] *Id.* § 1051.

[122] McGann v. H & H Music Co., 946 F.2d 401, 407 (5th Cir. 1991) (rejecting plaintiff's contention that altering an employee benefits plan which results in an identifiable employee, or group of employees, being treated differently from other employees, is discriminatory).

B. *Finding Relief Under GINA*

Relief for complainants subjected to unlawful employment practices include rehiring or reinstatement, back pay, back pay plus interest, or other equitable relief—as well as the issuance of an injunction that prevents the employer from engaging in further discriminatory practices.[123] Title VII statutory damages include both compensatory and punitive damages.[124] "[C]ompensatory damages . . . for future pecuniary losses, emotional pain, suffering, inconvenience, mental anguish, loss of enjoyment of life, and other nonpecuniary losses, and the amount of punitive damages" are limited to a fixed dollar amount, based on the number of employees in a company.[125] Plaintiffs may also request a jury trial.[126]

The enforcement provisions of Title VII include fee-shifting provisions allowing for payment of reasonable attorney's fees and costs to a prevailing party.[127] A court may award attorney's fees to a party that succeeds "'on any significant issue in litigation which achieves some . . . benefit . . . [he or she] sought in bringing [the] suit.'"[128] A party does not need to succeed on all issues in order to prevail.[129] It is only necessary to establish that the party has obtained some relief on the merit of a claim at the "outer boundary of the term 'prevailing party.'"[130]

C. *GINA Doesn't Really Help Workers*

With its broad language, widely-inclusive relative pool, jury trial, attorneys' fees, and costs, how could GINA not be the best thing that ever happened to a disgruntled employee? Well, it may be. It is possible that some employee who knows he is on the verge of being fired when GINA becomes effective will find a way to get his genetic information in front of the boss before the axe falls. Despite its attempts to protect workers, GINA is flawed. It doesn't protect all workers, and it could make the situation worse for some workers. GINA is not applied fairly to those workers

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[123] 42 U.S.C. § 2000e-5(g)(1) (2006).

[124] *Id.* § 1981a(a)(1). *But see* Huckabay v. Moore, 142 F.3d 233, 241 (5th Cir. 1998) (holding that "§ 1981a does not create a new substantive right or cause of action," but "provides an additional remedy for 'unlawful intentional discrimination . . . prohibited under [other statutes]'" (quoting 42 U.S.C. § 1981a(a)(1))).

[125] 42 U.S.C. § 1981a(b)(3).

[126] *Id.* § 1981a(c)(1).

[127] *Id.* § 2000e-5(k).

[128] Farrar v. Hobby, 506 U.S. 103, 109 (1992) (quoting Hensley v. Eckerhart, 461 U.S. 424, 433 (1983)).

[129] Easterling v. City of Orlando, No. 6:05-cv-855-Orl-22GJK, 2008 WL 3889612, at *9 (M.D. Fla. Aug. 20, 2008).

[130] *Id.*

whom it does cover and is likely to result in an increase in insurance rates, which will be borne across the board by all insureds.

1. GINA Does Not Cover All Employees Who Need Protection

GINA does not protect every worker. Approximately 11.6 million people in this country are currently unemployed.[131] A year ago nearly 2.7 million of them had jobs,[132] and, with the current economic crisis, unemployment lines could be flooded with hundreds of thousands more. Job-seeking workers would be protected from employment discrimination in hiring decisions based on genetic information, but most employers deny that they would test for genetics if they could.[133]

If employers do want to test, they could easily get around the laws through a loophole in the ADA regarding genetic testing in the workplace after an offer is made, but prior to the start of employment.[134] To illustrate, an employer could make a job offer conditioned on medical tests,[135] which might include genetic tests, and later withdraw the offer.[136] The prospective employee might never know if the employer conducted a genetic test or withdrew the job offer based on the results.[137]

GINA does not apply to companies with fewer than fifteen employees.[138] In 2006, more than 21.5 million employees, or 18% of the American private sector workforce, were employed by a company with zero to nineteen workers.[139] Of those, approximately 13 million worked for companies with fewer than ten employees.[140] Clearly, GINA fails to protect many millions of Americans.

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[131] U.S. Bureau of Labor Statistics, Economic News Release: Employment Situation Summary, http://www.bls.gov/news.release/empsit.nr0.htm (last modified Feb. 6, 2009) (last visited Feb. 17, 2009).

[132] *Id.*

[133] Baldas, *supra* note 53.

[134] *See id.*

[135] 42 U.S.C. § 12112(d)(3) (2006).

[136] *See id.*; Baldas, *supra* note 53; *see also* Kelly Cahill Timmons, *Accommodating Misconduct Under the American with Disabilities Act*, 57 FLA. L. REV. 187, 190 n.14 (2005) (emphasizing that "[c]ourts have held that persons who have been subjected to medical examinations and inquiries prohibited by the statute have standing to sue under the ADA, even if they are not disabled" (citing Roe v. Cheyenne Mountain Conference Resort, Inc., 124 F.3d 1221, 1229 (10th Cir. 1997))).

[137] *See* Baldas, *supra* note 53.

[138] Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, § 201(2)(B), 122 Stat. 881, 906 (to be codified at 42 U.S.C. § 2000ff(2)(B)).

[139] U.S. Census Bureau, 2006 County Business Patterns: Number of Firms, Number of Establishments, Employment, and Annual Payroll by Employment Size of the Enterprise for the United States, All Industries 2006, *available at* http://www.census.gov/csd/susb/susb06.htm (follow "U.S., all industries" hyperlink).

[140] *Id.*

2. An Inherent Unfairness in Protecting Employees

GINA applies only to asymptomatic individuals who are genetically predisposed to an illness, but it does not protect individuals who are unfortunate enough to actually manifest the same illness from unknown factors.[141] To use Mark Rothstein's example of breast cancer, an employee who tested positive for the BRAC-1 gene would have protection under GINA as long as she was asymptomatic.[142] If she actually developed breast cancer, then GINA would cease to protect her from employer discrimination.[143] Further highlighting the limited, and unfair, application of GINA, the employee with genetic markers is protected while the woman at the next desk who developed breast cancer from unknown factors would not be protected.[144] Rothstein argues this is not a congressional oversight, but "a symptom of the broader problem of the lack of distributive justice in an individual health insurance market based on individual medical underwriting."[145] Such a result is inherently unfair.

3. Insurance Rates Will Increase for Everyone

The insurance industry was very emphatic and direct in its warnings to Congress that, if GINA passed, insurance rates would increase.[146] Janet Trautwein, Executive Vice President and CEO of the National Association of Health Underwriters, testified: "It is extremely important that lawmakers recognize . . . the impact their actions will have on the cost of health insurance today and in the years ahead. Great care should be taken to craft legislation that . . . will [not] impede the normal underwriting process and increase the cost of coverage."[147]

Because individual policies tend to be written when a person is sick,[148] the individual policy market is the most expensive and the most sensitive to cost increases, making it critical that an underwriter is able to assess risk without restriction on significant health data.[149] By including the individual policy market in GINA, and thus denying underwriters the ability to obtain important familial history from individuals, the underwriter will not have

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[141] Mark A. Rothstein, *Is GINA Worth the Wait?*, 36 J.L. MED. & ETHICS 174, 176 (2008).

[142] *Id.*

[143] *Id.*

[144] *See id.* (noting that GINA protects only the 5–10% of women who develop breast cancer from known genetic factors).

[145] *Id.*

[146] Trautwein 2007 Written Statement, *supra* note 79, at 154.

[147] *Id.* at 156.

[148] *Id.* at 152.

[149] *Id.* at 152–53.

access to the necessary health information.[150] Insurance companies will therefore rate all policies, group and individual, at the highest cost basis of a sick person in an individual policy.[151] The healthy will subsidize the unhealthy; the employer-sponsored insured will subsidize the uninsured. The small-employer market, which employs approximately 38% of all workers,[152] will feel the most significant increases.[153] GINA has the potential to cause the greatest harm to those who are not under its protection.

4. Employers May Cancel Health Insurance

With increasing frequency, spiraling health insurance costs have forced companies to drop employer-sponsored health plans or pass on the cost to employees.[154] There is no federal law mandating employer-sponsored health insurance.[155] Health insurers also voiced concern that "[t]he possibility of virtually unlimited liability could prove to be a financial hardship for many employers and dampen their enthusiasm to offer benefits."[156] Faced with demands on all sides, employers may decide that providing health insurance for employees is simply not worth the expense and headache. Such a decision could severely strain the burgeoning ranks of America's uninsured and push health insurance out of reach of all but the wealthiest individuals.

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[150] *Id.* at 152.

[151] *Id.*

[152] *See* Nat'l Coal. on Health Care, Facts on Health Insurance Coverage, http://www.nchc.org/facts/coverage.shtml (last visited Feb. 17, 2009) (citing the latest data from 2005).

[153] Trautwein 2007 Written Statement, *supra* note 79, at 154.

[154] Nat'l Coal. on Health Care, Facts on Health Insurance Coverage, *supra* note 152.

[155] *See* Shaw v. Delta Air Lines, Inc., 463 U.S. 85, 91 (1983) ("ERISA does not mandate that employers provide any particular benefits."). Employees do not have "any substantive entitlement to employer-provided health benefits or any other kind of . . . benefits," and under ERISA, "[e]mployers . . . are generally free . . . for any reason at any time, to adopt, modify, or terminate" health care plans entirely. Curtiss-Wright Corp. v. Schoonejongen, 514 U.S. 73, 78 (1995) (citing Adams v. Avondale Indus., Inc., 905 F.2d 943, 947 (6th Cir. 1990)). *See also* Wheeler v. Dynamic Eng'g, Inc., 62 F.3d 634, 637 (4th Cir. 1995); Gable v. Sweetheart Cup Co., 35 F.3d 851, 855 (4th Cir. 1994); Wise v. El Paso Natural Gas Co., 986 F.2d 929, 935 (5th Cir. 1993) (quoting Phillips v. Amoco Oil Co., 799 F.2d 1464, 1471 (11th Cir. 1986), *cert. denied*, 481 U.S. 1016 (1987)); Owens v. Storehouse, Inc., 984 F.2d 394, 397 (11th Cir.1993) (citing Phillips v. Amoco Oil Co., 799 F.2d 1464, 1471 (11th Cir. 1986), *cert. denied*, 481 U.S. 1016 (1987)).

[156] *See* Nat'l Ass'n of Health Underwriters, NAHU Position on Genetic Testing, http://www.nahu.org/legislative/Genetic_position.pdf (last visited Feb. 17, 2009).

VI. CONCLUSION

It has been a decade since Terri Seargent received the results of her genetic tests. Congress used her story to argue the need for federal protection against genetic discrimination. Sadly, GINA would not have protected Terri. Terri was not asymptomatic; she had already begun expensive treatments for her disease when she was fired. Further, her small employer may have been exempt from the provisions of GINA if the company employed fewer than fifteen people.

GINA has been called "a solution in search of a problem."[157] It does not solve the problem of employment discrimination based on medical factors or asymptomatic genetic markers. While GINA protects some workers from employment-related genetic discrimination, its protection is not universal. The increased protection to the small percentage of individuals who purchase individual health insurance policies will be at the expense of workers in employer-sponsored groups who will be subsidizing the insurance. Effective protection of genetic information requires significant changes in the government's attitude toward providing health care for all citizens. Legislation is necessary to ensure that "sick people and those likely to get sick have a right to health care coverage."[158] Protecting workers from employment discrimination requires Congress to prohibit employer requests for medical records at any stage, from the offer stage through employment, unless the request is directly related to job function. GINA does not accomplish these goals.

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[157] Andrew Pollack, *Genetic-Discrimination Ban Moves Ahead in Congress*, N.Y. TIMES, Apr. 23, 2008, at C1.

[158] Rothstein, *supra* note 141, at 176.