

University of Pennsylvania Carey Law School

Penn Law: Legal Scholarship Repository

Faculty Scholarship at Penn Law

2013

Health Insurance, Employment, and the Human Genome: Genetic Discrimination and Biobanks in the United States

Eric A. Feldman

University of Pennsylvania Carey Law School

Chelsea Darnell

Wachtell, Lipton, Rosen & Katz

Follow this and additional works at: https://scholarship.law.upenn.edu/faculty_scholarship



Part of the [Civil Rights and Discrimination Commons](#), [Genetic Phenomena Commons](#), [Genetics Commons](#), [Health Law and Policy Commons](#), [Insurance Law Commons](#), [Labor and Employment Law Commons](#), [Law and Society Commons](#), [Medical Jurisprudence Commons](#), [Policy Design, Analysis, and Evaluation Commons](#), [Privacy Law Commons](#), [Public Law and Legal Theory Commons](#), [Science and Technology Law Commons](#), and the [Science and Technology Policy Commons](#)

Repository Citation

Feldman, Eric A. and Darnell, Chelsea, "Health Insurance, Employment, and the Human Genome: Genetic Discrimination and Biobanks in the United States" (2013). *Faculty Scholarship at Penn Law*. 1550.
https://scholarship.law.upenn.edu/faculty_scholarship/1550

This Article is brought to you for free and open access by Penn Law: Legal Scholarship Repository. It has been accepted for inclusion in Faculty Scholarship at Penn Law by an authorized administrator of Penn Law: Legal Scholarship Repository. For more information, please contact PennlawIR@law.upenn.edu.

Health Insurance, Employment, and the Human Genome: Genetic Discrimination and Biobanks in the United States

Eric A. Feldman*

Chelsea Darnell**

7.1 Introduction

Does genetic information warrant special legal protection, and if so how should it be protected?¹ This question has taken on greater urgency in the United States as genetic testing has become more common and biobanks have developed repositories for large amounts of genetic information. One central concern raised by the collection and storage of genetic and biomedical information is that individuals will increasingly experience privacy violations and discrimination.² Biomedical researchers worry that public fear of discrimination and privacy violations will limit their ability to collect and analyze genetic information in biobanks. As genetic testing advances and biobanks grow, such concerns will be amplified. The possibility that fear of genetic discrimination would cause people to refrain from genetic testing, which would in turn inhibit scientific research and the discovery of potentially life-saving medical interventions, was in large part responsible for the passage of legislation that addresses the potential threat of genetic discrimination in the US.

This essay examines the most recent (and indeed only) significant effort by the US government to prohibit genetic discrimination, the Genetic Information Nondiscrimination Act (GINA). Advocates worked for more than a decade to secure GINA's passage. In the end, we argue that the legislation is unlikely to have the positive impact sought by advocates of genetic privacy. In part, GINA disappoints because it does too little. Hailed by its promoters as "the first civil rights act of the 21st century," GINA's reach is in fact quite modest and its grasp even more so. But GINA also fails by trying to do too much, tying the hands of insurers and employers in ways that may fail to serve the interests of individuals or society more generally. In short, if genetic discrimination is a problem that needs to be solved, GINA is not the solution. Instead, the Act creates a number of new and possibly intractable problems that may be more troublesome than what it originally set out to resolve.

7.2 History of the Bill

GINA was signed into law on May 21, 2008, thirteen years after it was originally introduced in the House of Representatives. For a bill that floundered for over a decade, the vote in Congress was overwhelmingly positive; 94-0 in the Senate and 414-1 in the House. The lone

* Deputy Dean for International Affairs and Professor of Law at University of Pennsylvania Law School, efeldman@law.upenn.edu

** University of Pennsylvania Law School, cdarnell@law.upenn.edu

¹ See Eric A. Feldman, "The Genetic Information Nondiscrimination Act (GINA): Public Policy and Medical Practice in the Age of Personalized Medicine," 27 *Journal of General Internal Medicine* 743, 2012, for a discussion of the implications of GINA for primary care providers.

² Kaufman et al. 2009, p. 643-644

dissenter was Ron Paul, the maverick Texas Republican who opposes all legislation that he sees as expanding the federal government. The first version of GINA was introduced in 1995 by Representative Louise Slaughter, a Democrat from New York with a background in microbiology and public health. Despite bipartisan support, a series of efforts by Representative Slaughter and Senator Olympia Snowe (R-ME), and broad public support for the bill,³ GINA encountered various impediments. On the brink of passage in 2007, for example, GINA was stalled by Senator Tom Coburn (R-OK), an obstetrician who was concerned that it would encourage frivolous suits.⁴ In March 2008, he and ten Senators signed a letter to the White House requesting amendments. The lawmakers then agreed to create a “firewall” between employment and insurance sector regulation (so that a person could not sue both a group health plan and the employer for the same violation), and insert a clarification that insurers can continue to base decisions on an existing/expressed disease.”⁵ With those amendments, GINA finally became law.

7.3 GINA: Content of the Act:

The Genetic Information Nondiscrimination Act (GINA) is divided into two sections. The first, Title I, prohibits insurers from discriminating on the basis of genetic information while the second, Title II, does the same for employers. Title I of GINA applies to insurers in three basic ways: (1) group health insurers are prohibited from using genetic information about an individual to adjust group premium plans and insurers offering individual plans are prohibited from using genetic information to deny coverage, adjust premiums, or impose preexisting condition exclusion; (2) health insurers are not allowed to require or request genetic testing; and (3) health insurers are prohibited from requesting, requiring, or purchasing genetic information for underwriting purposes. Nothing in GINA, however, prevents group or individual insurers from considering manifested conditions for underwriting purposes. Insurers that do not comply with GINA are fined \$100 per day for each violation; the minimum penalty is \$2,500 (escalated to \$15,000 if the violation is more than *de minimis*).

Title II of GINA contains provisions related to employers with 15 or more employees. GINA aims only to isolate the treatment of genetic information by employers and does nothing to alter pre-existing regulations on the eligibility and use of health information by employers in federal and state law. Title II of GINA makes it illegal for an employer with more than 15 employees to discriminate with respect to hiring, compensation, terms, conditions or other privileges of employment because of genetic information. Employers are not allowed to “request, require, or purchase genetic information with respect to an employee or family member.” Title II is enforced under Title VII of the Civil Rights Act of 1964, which allows employees to recover up to \$300,000 in compensatory and punitive damages. If an employer intentionally violates GINA, a court can enjoin the employer from engaging in the practice and order affirmative action, such as the reinstatement or hiring of employees.

GINA’s broad definitions of the terms “family member,” “genetic information,” and “genetic test” mean that the Act prohibits insurers and employers from engaging in a wide array

³ “Besides the more than 200 health advocacy and business organizations that support this bill, recent surveys show 93 percent of Americans believe that employers and insurers should not be able to use genetic information to discriminate.” 153 Cong. Rec. H 4083, 4096 (Apr. 25 2007) (statement of Judy Biggert (R-IL13)).

⁴ Ironically, Senator Coburn’s official website press room reproduces a story critical of his hold-out period. See http://coburn.senate.gov/public/index.cfm?FuseAction=LatestNews.NewsStories&ContentRecord_id=9180ab87-802a-23ad-4e03-b65e171db230&Issue_id=

⁵ MacKenna 2008

of activities. Genetic information is defined as “information about [an] individual’s genetic tests, the genetic tests of family members of [the] individual, and the manifestation of a disease or disorder in the family member of [the] individual.” Family member is also defined broadly to encompass any dependent or relative up to the fourth degree. These broad definitions mean that there is a significant amount of information which employers and insurers are prohibited from using. The term genetic test is defined in both Title I and II as “an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes.” There is, however, a slight difference between the definitions of genetic test in Title I and Title II. Title I includes an exception for tests that are directly related to a “manifested disease, disorder, or pathological condition.” In making this distinction, lawmakers recognized that “there are important and necessary uses for non-genetic health information in the health insurance setting that are not applicable in the employment context.”⁶

7.4 The Case for GINA

Given the existence of both federal and state anti-discrimination laws, and the thin evidence that genetic discrimination is currently practiced, proponents of GINA struggled to justify the need for new legislation targeting genetic discrimination.⁷ In building their case, they largely relied on the historical case of discrimination against carriers of sickle cell anemia and anecdotal evidence of isolated instances of genetic discrimination as proof that GINA was needed. Sickle cell was their most powerful example. During the 1970s state governments began to screen and identify carriers of sickle cell anemia, a disease which afflicts African-Americans. The goal was to identify not only individuals suffering from the disease, but also healthy carriers. Genetic testing for sickle cell was justified by claims that those with the sickle cell gene might be hyper-susceptible to certain workplace toxins, even though such claims lacked empirical support.⁸ The discrimination (by both insurers and employers) that resulted from screening for sickle cell anemia was exacerbated when “state legislatures began to take steps in the area, and in the early 1970s began mandating genetic screening of all African-Americans for sickle cell anemia, leading to further fear and discrimination.”⁹ In response, “Congress in 1972 passed the National Sickle Cell Anemia Control Act, which withholds Federal funding from States unless sickle cell testing is voluntary.”¹⁰

In addition to the case of discrimination against carriers of sickle cell anemia, proponents of GINA presented anecdotal evidence of more recent instances of genetic discrimination. Representative Slaughter recounted the tale of Heidi Williams, who in 2004 testified that a large health insurance company had denied coverage for her two children because they were carriers of the gene for alpha-1 antitrypsin deficiency. Slaughter argued that “GINA will make these discriminatory practices illegal by prohibiting health insurers from denying coverage or charging higher premiums to a healthy individual because of a genetic predisposition, which means [they]

⁶ S. Rep. No. 110-48, at 28.

⁷ Existing legislation includes, for example, the Health Insurance Portability and Accountability Act, the Americans with Disabilities Act, Title VII of the Civil Rights Act, and a large number of state statutes that prohibit genetic discrimination by insurers and employers in at least some contexts.

⁸ S. Rep. No. 110-48, at 8 (citing Melinda B. Kaufmann, *Genetic Discrimination in the Workplace: An Overview of Existing Protections*, 30 LOY. U. CHI. L. J.393, 402–03 (1999))

⁹ S. Rep. No. 110-48, at 9 (citing 42 U.S.C. § 300(b)).

¹⁰ *Ibid.*

may never get the disease.”¹¹ Isolated anecdotal instances of alleged genetic discrimination and a historical case of genetic discrimination that has already been addressed by Congress were the bedrock of the argument for GINA. But they offered only weak evidence that genetic discrimination is occurring or that government action is necessary.

To justify Title II of GINA, proponents relied primarily on surveys indicating that genetic discrimination may be occurring in the workplace. The American Management Association conducted a “Workplace Testing Survey” in 2000 and found there were several instances in which members used what they understood to be genetic information in hiring and firing decisions.¹² Of 2,133 employers included in another survey, seven indicated that their companies performed what they thought was genetic testing of employees (that number was up from three in 1999). Of the seven, three reported performing genetic testing of job applicants and six reported performing genetic testing of employees. The Office of Technology Assessment conducted a similar survey in 1989 of Fortune 500 companies; of the 330 companies that responded, 12 admitted to conducting genetic tests of employees.¹³

Given the scant evidence of genetic discrimination, proponents had little choice but to emphasize the possibility of future discrimination rather than actual instances of discrimination. They pointed to the large number of genetic disorders and the millions of people affected to conclude that genetic discrimination *could* affect everyone. In arguing for passage of GINA, Representative Slaughter stated that “Already, over 15,500 recognized genetic disorders affect 13 million Americans, and . . . each and every one of us is in that category of carrying between 5 and 50 bad genes, or predicted genes.”¹⁴ Moreover, supporters of GINA argued that regardless of whether there is currently widespread genetic discrimination, fear of discrimination could dampen research efforts and inhibit scientific progress. This was emphasized by the Senate Committee on Health, Education, Labor, and Pensions (HELP), which published a report on genetic discrimination in 2007 finding that fear of discrimination is the most common reason for not participating in research on potentially lifesaving genetic testing for breast cancer and colon cancer. According to the report, more than one third of those who were eligible declined to participate in a genetic testing program; those who declined cited fears about the potential effect of test results on their health insurance coverage as the primary reason for their refusal.¹⁵ In the end, given the lack of evidence that genetic discrimination is currently a significant problem, GINA’s primary target appears to be the fear that genetic discrimination could become a serious issue in the future.

7.5 The Case Against GINA:

7.5.1 Criticisms of Title I

No one advocates genetic discrimination, and no politician wants to be seen as favoring the mistreatment of the genetically vulnerable. But Congress’s overwhelming support of GINA should not mask the various deficiencies of the legislation. Most significantly, GINA is a

¹¹ Id. at 4095.

¹² S. Rep. No. 110-48, at 6.

¹³ Id. at 7.

¹⁴ 153 Cong. Rec. H 4083, 4095 (Apr. 25 2007) (statement of Louise Slaughter (D-NY28)).

¹⁵ S. Rep. No. 110-48, at 5. See also Rothenberg 2007

response to an imaginary need—there is little evidence of genetic discrimination in the United States, and similarly little evidence that GINA will lead to increased participation in clinical research or a greater willingness among patients to pursue genetic testing. Proponents of the Act pointed to anecdotal evidence of discrimination and recounted discrimination against carriers of sickle cell anemia in the 1970s. Beyond that, there is scant evidence of actual genetic discrimination occurring in the United States. According to the Senate HELP Committee, for example, “[a]lthough surveys and polls demonstrate a fairly widespread fear of discrimination, there is little evidence or documentation of actual discrimination in health insurance. For instance, the American Academy of Actuaries notes that private insurers do not require applicants for insurance to undergo genetic testing or use genetic tests to limit coverage for preexisting conditions.”¹⁶ Noting “the apparent conflict between actual discrimination versus the fear or perception of discrimination,” the Senate HELP Committee nevertheless found the Act necessary to assuage (irrationally) worried consumers.¹⁷

In addition to prohibiting a type of discrimination that rarely if ever occurs, GINA represents an incomplete and flawed solution to the hypothetical problems it addresses. The Act prohibits discrimination only by a limited class of insurers, health insurers. It does not prohibit discrimination in other insurance contexts, notably life insurance, disability insurance, and long-term care insurance. The implication of such a limitation is that it is appropriate for insurers to use genetic information when writing insurance policies that do not fall within the scope of the Act. If the use of genetic information by the insurance industry is discriminatory in the health insurance area, so too would it be discriminatory *vis a vis* life insurance, and GINA should prohibit all insurers from using genetic information, not only a narrow subset of insurers.¹⁸

Even with regard to health insurance, GINA’s applicability is relatively limited. Most Americans with health insurance are covered by a group plan provided by their employer, with only 9% of Americans purchasing health insurance privately.¹⁹ When insurance companies price group plans, they evaluate the overall health characteristics (and claims history) of the group and set uniform premiums. Individual members of the group all pay the same amount for their health insurance.²⁰ Consequently, at least when it comes to group health plans, there is little opportunity for discrimination against individuals on the basis of genetic information. In the absence of GINA, insurers could raise rates for an entire group as the result of an individual’s genetic information, thus raising the possibility of discrimination against all members of the group. But such actions do not appear to have occurred in the past, and are highly unlikely to happen in the future, given the extremely ambiguous link between genetic information and increased health care costs. Thus, even in the field of health insurance, where GINA appears to boldly prohibit genetic discrimination, the applicability of the Act is limited by the fact that the insurers through which most Americans obtain their health insurance are unlikely to be in a position to use genetic

¹⁶ S. Rep. No. 110-48, at 7. “Another study of insurance practices found there are almost no well-documented cases of health insurers either asking for or using presymptomatic genetic test results in their underwriting decisions. The same study found that ‘some insurers clearly do use family history information for important disease categories such as heart disease, cancer, and diabetes, but they do so only to look for or evaluate other signs of existing or prior disease, not to predict the onset of future health problems.’” *Id.* at 8.

¹⁷ *Id.* at 8.

¹⁸ It is not clear why GINA did not prohibit all insurers from using genetic information. One possibility is that the politically powerful life insurance industry would have effectively opposed such legislation.

¹⁹ DeNavas et al. 2008

²⁰ Because the insurance industry is heavily regulated by state governments, there is significant variation in how companies engage in community rating and experience rating when setting health insurance premiums.

information in a discriminatory manner.

The most challenging question raised by GINA is whether the use of genetic information by insurers should be condemned as inappropriately discriminatory. Determining what constitutes discrimination is always contentious, but within the insurance industry that job has been made easier by the National Association of Insurance Commissioners (NAIC). NAIC's Model Unfair Trade Practices Act prohibits "making or permitting any unfair discrimination between individuals of the same class and of essentially the same hazard in the amount of premium, policy fees or rates charged..."²¹ Under this definition, for example, it is clear that it would be unfairly discriminatory to price health insurance differently for two people if they both presented identical risk profiles. It would not, however, be unfairly discriminatory to price one of their insurance policies higher if one of them had suffered two heart attacks and the other had a healthy heart. It would also be unfairly discriminatory to price insurance differently for two people if they both tested positive for a gene connected to breast cancer and were the same in all other respects, but not unfairly discriminatory to price insurance differently if one of the individuals tested positive for the gene and the other did not. As long as there is a reasonable basis for believing that testing positive for a particular gene can have an impact on someone's long term health profile and corresponding health care costs, then under the insurance industry's definition of discrimination it does not appear as though pricing insurance plans differently based on genetic information would be unfairly discriminatory.²²

Since its inception, classifying risk and making distinctions between individuals based on their risk profiles has been the lifeblood of the insurance industry. Evaluating individuals based on the risks they present, and distinguishing between individuals based upon their different risk profiles, should be considered discriminatory only when the basis of such distinctions is inappropriate. Insurers have long taken into account gender, medical history, weight, alcohol consumption, and smoking, for example, when evaluating an individual's future health trajectory. Such information may be useful for determining different health risks and potential costs of providing health care treatment. If fine grained genetic tests provided accurate information about individual proclivities to certain medical conditions, then using that information in insurance coverage decisions may not run afoul of the notion of unfair discrimination in the insurance industry, or perhaps of broader societal views of discrimination. Higher risk individuals end up consuming more insurance than lower risk individuals; when insurers are able to determine which individuals pose a higher risk then they will charge those individuals a higher premium to compensate for the fact that they are likely to use more insurance in the future. Indeed, some European nations that enacted genetic discrimination legislation earlier than the US have found that legal prohibitions on genetic discrimination have increased the degree to which insurers factor 'lifestyle' risks into their underwriting practices. The result is that people who smoke, or are obese, or present other types of lifestyle risks, face greater levels of discrimination (which are generally manifested as higher insurance premiums) than before the passage of legislation prohibiting genetic discrimination.²³

²¹ ...

²²See Tom Baker, ed., *Insurance Law and Policy*, section re: "Topics in Substantive Insurance Regulation," subsection "Insurance Risk Classification," [FIND PRECISE CITE], for a discussion of risk classification and fair discrimination: "As understood by many people in the insurance business, classifying people according to their risk is fair and gives them an incentive to arrange their affairs so that they pose a lower risk."(p.748?) In other words, insurers believe that it is fair for people to pay more for insurance if they present higher risks, but unfair to charge people different premiums if they are of the same class and represent the same hazards.

²³ Van Hoyweghen and Horstman 2008

If insurers cannot collect the information necessary to evaluate individual risk profiles, then they will raise all premiums and lower risk individuals will end up subsidizing higher risk individuals. According to the prevailing values of the US insurance industry and its embrace of experience rating, the greatest injustice occurs when insurers do not use all available information (including genetic information if it is a reliably predictive indicator of an individual's risk potential) to distinguish between the insured population, and lower risk individuals are charged the same amount as higher risk individuals. Such an approach to insurance runs the risk of adverse selection, making it less likely for low risk than high risk individuals to buy insurance, and increasing the average risk of those in the pool.²⁴

If one were to object to experience rating and challenge the usual insurance industry practice of treating individuals differently on the basis of the future risks that they pose, then the distinction that GINA draws between genetic information and manifested diseases becomes suspect. Korobkin and Rajkumar argue in *The New England Journal of Medicine* that a person whose colonoscopy finds an actual disease (a manifested condition not protected by GINA) bears “no more responsibility” for their increased risk of future treatment than those whose genes predispose them to illness (a genetic predisposition protected by GINA).²⁵ GINA further complicates the problem: “Because insurance companies may no longer make use of clearly relevant information such as family history in their risk assessment, they will rely even more heavily on current health status when setting rates, even when it has only slight value in predicting future illness. In a post-GINA world, not only will the very sick have even more trouble obtaining affordable insurance, but so will the mostly well. Additionally, while those who get bad news from genetic tests will rely on GINA to obtain health insurance at a subsidized rate, those whose genes put them at lower risk can opt out entirely or, more likely, purchase insurance with higher deductibles, greater cost sharing, and more exclusions. If the lower-risk portion of the population segregates itself into what is essentially a separate insurance pool, the goal of spreading the cost of genetic risk cannot be satisfied”.²⁶

One response to this challenge is to abandon the regulatory efforts of GINA and leave health insurance to market forces. Given the recent passage of the Patient Protection and Affordable Care Act, however, it appears that the US health insurance industry is likely to more heavily regulated in future, not less. Another response, embraced by Korobkin and Rajkumar, is to admit that the distinction between genetic information and other immutable characteristics is arbitrary and to move toward a system that prohibits insurance companies from taking into account any health information, not just genetic information for underwriting policies. This would create one large community rate, with the only difference in premiums being driven by those circumstances within a person's reasonable control.²⁷

In addition to the conceptual challenges of collecting and evaluating individual genetic information, there is also a practical concern. As of 2011, genetic information is not usefully predictive of health outcomes. Testing can reveal the existence of specific genes in an individual's DNA, but scientists are not able to make useful predictions about the increased likelihood that a particular individual will end up manifesting a particular condition. Moreover, genetic testing is only available for a limited number of the many diseases that affect humankind.

²⁴ As the Patient Protection and Affordable Care Act of 2010 is implemented, some of these issues will lose their salience.

²⁵ Korobkin and Rajkumar 2008

²⁶ *Id.* at 336

²⁷ *Id.* at 337.

Since the use of genetic information is not usefully predictive of future health outcomes, companies that rely on genetic information are at a competitive disadvantage. For that reason, at least currently, health insurers have little practical use for genetic information. Even if a company chose to ignore the economic irrationality of collecting and using genetic information in underwriting decisions, individuals who believed they had suffered from genetic discrimination would be able to pursue their claims under one of several already-existing federal or state laws. GINA provides few if any new useful legal tools to potential plaintiffs.

7.5.2 Criticisms of Title II

Although employment discrimination is intolerable, matching people's skills, abilities, and qualifications to particular jobs is the lifeblood of human resources departments throughout the nation. For a commercial airline hiring pilots, for example, it is critical that potential employees not only have technical knowledge about how to fly a plane, but also have good reflexes, react well under pressure, and be in good physical condition. It would certainly be undesirable to have pilots who were particularly susceptible to sudden and unpredictable seizures or who suffered from narcolepsy. A recent study by Japanese researchers raises challenging questions about the use of genetic information in the employment setting. According to that study, there is a genetic variant that is linked to a much higher than average risk of narcolepsy.²⁸ In addition, scientists have identified at least twelve forms of epilepsy with a genetic basis.²⁹ If science progresses to the point that genetic tests can provide scientifically reliable information about whether a given individual has the gene for narcolepsy or epilepsy, and can accurately predict the likelihood that the condition would manifest within a given amount of time, should airlines ignore that information when they hire pilots? Should they use it to screen out particular employees?

These are challenging questions, ethically and legally. But at least in contexts like commercial aviation, erring on the side of caution is the most appropriate response. When boarding a plane, people should know that the airline has examined all relevant, reliable, and available information to ensure that the pilot is not likely to have a seizure or a narcoleptic attack during the flight. That includes ambiguous but suggestive information from genetic tests, as well as information about an applicant's family history. GINA prohibits airlines from gathering and using both types of information in their hiring decisions. Of course, if science has not progressed to the point of being able to identify a relevant genetic variant, or provide useful information about the likelihood of that variant leading to the manifestation of the disease, then genetic information cannot and should not be used in the employment setting. And there will always be disagreement about how to interpret the science, how to evaluate particular data, and how to understand the relative risks associated with particular genes. But under GINA's broad definition of genetic information, employers are prohibited from collecting and using information that is at least arguably relevant to an individual's fitness for a particular position. GINA puts an end to an important conversation about genetic information, when society should be engaging with the meaning of that information and evaluating if, how, and when it should be used.

²⁸Miyagawa et al 2008

²⁹ National Center for Biotechnology Information, "Genes and Disease," <http://www.ncbi.nlm.nih.gov/books/NBK22237/>.

7.5.3 Litigating Genetic Discrimination

The paucity of litigation over genetic discrimination further supports the view that such discrimination is extremely rare, and that GINA is likely to provide potential plaintiffs with few new legal tools in those rare circumstances in which they chose to litigate. There are only two regularly cited cases related to genetic discrimination. In the first, *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260 (9th Cir. 1998), Lawrence Berkeley Laboratory, a research institution operated jointly by State and Federal agencies, tested unknowing employees for syphilis, sickle cell trait, and pregnancy. In its opinion, the court reiterated that “[t]he constitutionally protected privacy interest in avoiding disclosure of personal matters clearly encompasses medical information and its confidentiality.”³⁰ The court acknowledged that “cases defining the privacy interest in medical information have typically involved its disclosure to “third” parties, rather than the collection of information by illicit means.”³¹ However, the court ultimately held that “it goes without saying that the *most basic* violation possible involves the performance of unauthorized tests--that is, the non-consensual retrieval of previously unrevealed medical information that may be unknown even to plaintiffs.”³² The tests done by Berkeley labs were found to violate the Fourth Amendment search and seizure rights as well as the Due Process Clause of the Fifth or Fourteenth Amendments.³³ Without GINA, in other words, the *Norman-Bloodsaw* court was able to remedy an instance of genetic discrimination.

The second case involving genetic discrimination, *Burlington Northern Santa Fe Railroad Company v. EEOC*, was filed on February 9, 2001 by the EEOC; it was the first lawsuit filed by the EEOC alleging genetic discrimination under the American’s with Disabilities Act (ADA).³⁴ Many commentators claim that the Railroad, in its search for a gene it believed contributed to its employees’ carpal tunnel syndrome, conducted tests on asymptomatic employees without their knowledge or consent. In reality, the EEOC never claimed that the railroad tested asymptomatic employees. Instead, the EEOC’s claim involved employees who said that they had developed work-related carpal tunnel syndrome and that the railroad had asked them to undergo a 34 part medical evaluation, which included a blood test looking for a genetic marker. Employees refusing the test claimed that the railroad engaged in retaliatory behavior. One employee, for example, claimed to have been threatened with termination for failing to submit to the blood test.

The EEOC alleged that the Railroad’s genetic testing was a violation of the ADA, but that theory was never tested because the case was settled. As part of the settlement agreement, Burlington Northern Santa Fe Railroad Company paid the EEOC and the Claimants \$2.2 million and agreed not to conduct genetic testing. The Railroad did not admit fault, and the settlement contained a clause stipulating that “The parties agree that this Agreement does not constitute an admission by BNSF of any violation of the ADA, or any other anti-discrimination or other

³⁰ *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1269 (9th Cir. 1998).

³¹ *Id.*

³² *Id.* at 1269.

³³ *Id.* Of course, the Constitution only protects persons from state action. The use of genetic information by health insurance companies, plans, researchers and private employers does not raise constitutional problems and was what prompted genetic information nondiscrimination legislation. S. Rep. No. 110-48, at 7.

³⁴ *EEOC v Burlington N. Santa Fe Railway Company*, Civ No 01-4013 MWB, (N.D. Iowa, Feb. 8, 2001) See Press Release, EEOC Settles ADA Suit against BNSF for Genetic Bias, <http://www.eeoc.gov/eeoc/newsroom/release/4-18-01.cfm> (last visited Feb. 20, 2010) (announcing settlement).

laws.”³⁵ Although the EEOC’s theory that genetic testing was a violation of the ADA was not tested, there is at least a possibility that the ADA can be used to protect Americans from genetic discrimination, making additional legislation to prevent genetic discrimination (GINA) superfluous.

Even cases that directly reference GINA provide little evidence that GINA is a valuable legal tool. Although the legislation is still quite new, only eight reported cases have mentioned GINA since its enactment in 2008. Six of them were brought under Title II of GINA, while the remaining two only tangentially reference the Act. None of the cases were at all dependent upon GINA; in the absence of the Act, plaintiffs could (and did) assert their discrimination claims by referencing other legal standards. And the six GINA-related claims have not fared well in the courts. Three were dismissed for failure to state a claim; one for both failure to state a claim and failure to exhaust administrative remedies.³⁶ One was filed against the Department of Education in Guam and was dismissed on jurisdictional grounds. The remaining claim brought under GINA was dropped by the plaintiff.³⁷ Over time, the situation could change. But at least so far, GINA has not served as a useful legal tool for those who believe they have been victims of genetic discrimination.

7.6 Conclusion

In the absence of evidence that genetic discrimination by insurance companies or employers is occurring in the US, it is difficult to justify federal legislation preventing such discrimination. Even if genetic discrimination were occurring, it is not clear that GINA is the appropriate response. If discrimination based on genetic information at the hands of insurers were a problem, then the prohibition on discrimination should apply to all insurers, not only health insurers. GINA also falls short in the workplace; although employment discrimination is clearly undesirable, there are some circumstances in which we might want employers to use genetic information to ensure that candidates are, and are likely to remain, physically qualified for particular positions. In both the insurance and employment settings, it is critical to appreciate the difference between unfair discrimination and appropriate distinction. The former bespeaks prejudice, bias, and ignorance, the latter a rational response to the different inherent qualities of individuals. The border between discrimination and distinction is often blurry, but in the context of genetic information it is a line that society must critically engage. As biobanks continue to grow and more genetic information is collected, the threat of genetic discrimination in the US will only increase and it will become even more important for society to engage these issues. GINA might temporarily serve to assuage fears that people have related to the collection and storage of their genetic information by biobanks; however, if genetic discrimination truly becomes a problem GINA will not adequately address it. Ultimately, GINA is a solution in search of a problem; it is an unnecessary piece of legislation that creates more problems than it

³⁵ EEOC and BNSF Settle Genetic Testing Case under Americans with Disabilities Act, <http://www.eeoc.gov/eeoc/newsroom/release/5-8-02.cfm> (last visited Feb. 20, 2010) (elaborating on settlement conditions)

³⁶ See *Bullock v. Spherion*, No. 3:10-cv-465, 2011 WL 1869933 (W.D.N.C. May 16, 2011); *Robinson v. Starplex/CMS Event Security*, No. CV-10-723-HU, 2011 WL 1541290 (D. Or. Mar. 15, 2011); *Citron v. Niche Media/Ocean Drive Magazine*, No. 10-24014-CIV, 2011 WL 381939 (S.D. Fla. Feb. 2, 2011); *Benoit v. Pennsylvania Board of Probation and Parole-West Division*, No. 094047, 2010 WL 481021 (E.D. Pa. Feb. 9, 2010); *Capulong v. Dep’t of Education of Guam*, No. 10-00005, 2011 WL 1134986 (D. Guam Mar. 24, 2011).

³⁷ *Armes v. CSX Transportation, Inc.*, No. CCB-11-112, 2011 WL 2471476 (D. Md. June 20, 2011)

solves.

References

Baker T (2008) Insurance Law and Policy: Cases and Materials. Aspen Publishers, New York.

DeNavas-Walt C, Proctor B D, Smith J C (2008) Income, Poverty, and Health Insurance Coverage in the United States: 2007. <http://www.census.gov/prod/2008pubs/p60-235.pdf>. Accessed 20 February 2010

Kaufman D J (2009) Public opinion about the importance of privacy in biobank research. *Am J Hum Genet* 85:-643-654

MacKenna R (2008) US Senate Approves Genetic Anti-Discrimination Legislation, http://www.bionews.org.uk/page_13370.asp. Accessed 20 February 2010

Miyagawa T (2008) Variant between CPT1B and CHKB associated with susceptibility to narcolepsy. *Nature Gen* 40:1324-1328

Rajkumar K, Rajkumar R (2008), The genetic information nondiscrimination Act — A half-step toward risk sharing. *N Engl J Med* 359: 335-337

Rothenberg K (2007) Protecting Workers from Genetic Discrimination: Hearing before the Subcomm.e on Health, Employment, Labor and Pensions of the H. Comm. on Education and Labor. U.S. Government Printing Office, Washington

Van Hoyweghen I, Horstman K (2008) European practices of genetic information and insurance: lessons for the genetic information nondiscrimination Act. *JAMA* 300:326-327