As rapidly evolving technologies provide more information about disease-related genes in human DNA, there is an increase in genetic screening for predisposition for a variety of diseases. Knowledge of genetic information provides significant benefits and drawbacks. Potential misuse of genetic information, particularly by employers or insurance companies, is a realistic possibility. Genetic information is often attainable via electronic medical information databases, heightening concerns that these data will be accessed by third parties and used for discriminatory purposes. Many lawmakers believe that potential harm specifically resulting from misuse of genetic information is so great that legal protection is required. Key words: Americans with Disabilities Act, genetic privacy, genetic testing, medical privacy.

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The range of genetic tests and other genetic information has proliferated in recent years, largely as a result of the Human Genome Project. Genetic tests can provide information about an individual’s likelihood of passing genetic conditions on to his or her children or this person’s increased risk of future disease, disability, or even early death. Genetic testing also can confirm a diagnosed syndrome, allowing identification of appropriate treatment. However, along with the benefits of genetic science come the dangers of lost privacy and potential misuse of genetic information: “The primary public concerns are that insurers will use genetic information to deny, limit, or cancel insurance policies or employers will use genetic information against existing workers or to screen potential employees. Because DNA samples can be held indefinitely, there is the added threat that samples will be used for purposes other than those for which they were gathered.” With computer networks, electronic medical records, including genetic information, are increasingly accessed.

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copied, and moved across administrative, legal, and national jurisdictions, thus heightening privacy concerns.4

Public concern about the use of medical information, particularly genetic information, by third parties may have significant impact on the health care system. The threat of disclosure of one’s personal medical information is an important consideration that may serve to undermine the doctor-patient relationship and threaten the quality of health care.5-7 For example, a 1998 national survey of 1,000 people conducted by the federally funded National Center for Genome Resources found that 36 percent of those surveyed would probably not take genetic tests and 27 percent would definitely not take a genetic test if employers and health insurers could get access to the test results.8

Many privacy advocates have echoed this sentiment, arguing that without legal privacy and antidiscrimination protection patients will lie to their doctors about genetic risk factors, thereby delaying important clinical decisions. This will, in turn, drive up health costs. Researchers at Georgetown University conducted a study in 1995 and found that of the 332 people surveyed, fears of workplace discrimination prevented one in ten respondents from getting tested for genetic traits linked to breast cancer, cystic fibrosis, Huntington’s disease, colon cancer, or other conditions, even though early detection and treatment could possibly improve their lives.8

Individuals’ refusals to get genetic tests due to fear of discrimination also can have negative consequences for scientific research. Medical researchers have noted that individuals are refusing to participate in long-term medical studies to assess their risk of developing genetically linked diseases because they fear their involvement in the studies would be a red flag on their medical records, which would invite genetic discrimination.8

Workers have reason to be concerned about genetic discrimination. In 1989 Northwest Life Insurance surveyed 400 employers and found that, by the year 2000, 15 percent planned to check the genetic status of prospective employees and their dependents before making job offers.1 Representative Slaughter told the Congress “More recently, a University of Illinois survey of 84 Fortune 500 companies showed that 35 percent used medical records including genetic information to make decisions about hiring, firing and promotions.”9(p3) A 1996 study conducted by a team of medical researchers documented more than 200 cases in which individuals with a genetic predisposition to certain diseases reported a range of discriminatory actions, made on the basis of genetic information, by employers and others.7 The subjects of the study were asymptomatic at the time the discriminatory actions were alleged to have taken place.

At present, most cases of genetic discrimination in employment remain anecdotal, and few have been tested in the courts. In her testimony at a Senate hearing on genetic discrimination, Representative Louise M. Slaughter6 related several examples of discrimination, including an individual who, after years of excellent performance reviews and promotions, was summarily dismissed from her job after her employer discovered she was receiving a preventive treatment for a genetic condition. This action left the employee and her family without her income and deprived her of insurance coverage for the treatment that was keeping her healthy and fully functional. Other victims of genetic discrimination include a woman who was
fired the day after she told her employer of the diagnosis of a genetic skeletal disorder and a man with a sex chromosome disorder whose job offer was rescinded following a preemployment physical after the doctor wrote the name of the disorder on his medical report. "In rescinding the job offer and explaining why, the employer told the applicant that he would deny the conversation in the future if asked."[p.31]

In *Norman-Bloodshaw v. Lawrence Berkeley Laboratory*, workers were tested without their knowledge or consent. Marya Norman-Bloodshaw received a physical examination and gave a blood sample when she started work as an accounting administrator at the Lawrence Berkeley National Laboratory in California. Without her knowledge or consent, her employer tested her for syphilis, pregnancy, and sickle cell traits. The testing was discovered sometime later when Norman-Bloodshaw’s mother, a nurse, was reviewing her medical records and asked her daughter why the tests had been done. After learning about Ms. Norman-Bloodshaw’s experience, some of her colleagues requested their own medical records from Lawrence Berkeley and found similar abuses. As a result, seven workers eventually filed a class action suit, alleging that blacks and Hispanics had been disproportionately tested for traits such as sickle cell.[10] Their case was initially dismissed, but on appeal the Ninth Circuit held that the plaintiffs could bring their Title VII claim to trial on the grounds that the employer selectively administered examinations to African Americans (for sickle cell) and to women (for pregnancy). Plaintiffs also were permitted to go to trial on the grounds that performing the tests on the plaintiffs without their knowledge or consent violated prevailing medical standards and invaded their privacy.[10] However, the Ninth Circuit upheld the dismissal of the Americans with Disabilities Act (ADA) claim on the grounds that no job-related action was taken against the employees, there were no proven violations of the ADA’s confidentiality provisions, and the scope of the medical examinations did not violate the ADA.[10]

The issue of genetic information discrimination in insurance, primarily health insurance, also has generated widespread attention. Health maintenance organizations (HMOs) and insurers in general have a tremendous incentive to obtain medical information suggesting that an individual presents a current or future risk of requiring costly health care. "One of the many debates surrounding genetic information is that insurance companies are charging certain applicants or insureds increased premiums or denying them benefits because these individuals are at a higher risk of developing a certain disease."[11][p.426] Moreover, "The history of disease or other preexisting condition has been used as a reason to deny health insurance to many individuals of both sexes, and genetic disease as well as susceptibility may be considered pre-existing conditions."[12][p.266]

Employers who provide insurance plans for their employees are vulnerable to pressure from insurers who wish to avoid providing services for such individuals. The pro-

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**Insurers have a tremendous incentive to obtain medical information suggesting that an individual presents a current or future risk of requiring costly health care.**
cess of gene mapping and sequencing has developed information that increasingly enables insurance companies and employers to affordably use genetic information to determine insurability. One study indicates that up to 22 percent of people with certain genetic disorders such as phenylketonuria and Huntington’s disease are denied insurance coverage based on this determination.13

So long as employers cover the majority of the insured, genetic information entails risks of discrimination in hiring, firing, advancement, and employment practices in general. In a free enterprise system, insurance companies and employers have legitimate grounds for arguing that statistical risks, as calculated by actuarial data, justify their selective practices toward customers and workers. Unless laws restrict these practices, individuals are likely not only to resist disclosure of identified genetic conditions, but also to resist testing that might otherwise yield information they would like to have. Negative test results are usually a source of relief and reassurance. But even positive results, whether they identify “disease conferring” or “susceptibility-conferring” genetic mutations, are useful to and desired by some individuals. Individuals at risk for Huntington disease, for example, might consider this information crucial to their reproductive plans; those at risk of familial breast or ovarian cancer would surely find it relevant in deciding whether to undergo prophylactic surgery.15p 267

PROTECTION UNDER STATE LAW

At the state level, there is a hodge-podge of laws attempting to protect privacy and prevent abuse of medical information generally or genetic information specifically. Most state laws have been enacted over the past three years, and the majority are narrow in scope.14 Thirty-two states have laws purporting to provide some form of protection: “Some guard against misuse of the knowledge, some seek to manage dissemination of the knowledge before it gets misused, and a few grant the right to object before a technician spins out a genetic profile in the first place.”15p A1A7

However, employers in most states are not prevented from requiring medical examinations, including genetic testing, of workers or prospective employees. Employers who do not perform the test directly may still have access to medical records containing information about a person’s predisposition to disease.16 Given the need for increased protection and uniformity in this area, it is widely believed that comprehensive federal legislation is needed to protect information privacy adequately and prohibit genetic discrimination. However, there is considerable disagreement as to the specifics of that legislation.

PROTECTION UNDER FEDERAL LAW

No federal legislation has been passed relating to genetic discrimination in individual insurance coverage nor is there comprehensive legislation that specifically prohibits genetic discrimination in the workplace. However, there is some federal protection against genetics-based bias:

1. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides limited federal protection from genetic discrimination. HIPAA is the only piece of federal legislation that provides specific protection from genetic discrimination. It prohibits group health plans from using genetic information as a basis for denying or limiting eligibility for coverage or for charging an individual more for coverage, and it explicitly provides that genetic information in the absence of a current diagnosis of illness shall not be considered a “pre-existing condition.”13
In December 2000, the Department of Health and Human Services (DHHS) issued comprehensive medical privacy regulations pursuant to HIPAA’s authorization. The final regulations are expected to take effect approximately 26 months after their final approval by Congress and the Bush administration. The regulations provide much-needed medical information privacy protection, including genetic information. Provisions include protection against unauthorized use of medical records for employment purposes. Companies that sponsor health plans are prohibited from accessing personal health information held by the plan for employment-related purposes without authorization from the patient. The new regulations also require providers and health plans to give patients a clear written explanation of how they can use, keep, and disclose their health information. Patients will be able to access their records and request amendments. A history of most disclosures also must be made accessible to patients. Specific, informed, voluntary patient consent is required before information can be disclosed for nonroutine uses and most non–health care purposes such as use by employers to make personnel decisions, by financial institutions determining mortgages and other loans, or by selling mailing lists to interested parties such as life insurers. The new regulations provide both civil and criminal penalties for covered entities that misuse personal health information.\textsuperscript{17}

Unfortunately, HIPAA is limited in scope. For example, it covers employer-based and commercially issued group health insurance; private individuals seeking health insurance in the individual market are not protected. Many entities, including life insurers and workers’ compensation programs, are still not regulated under HIPAA. Thus, they are not prohibited from using and disclosing medical information. The law also does not prohibit employers from refusing to offer health coverage as part of their benefits packages. Finally, HIPAA’s protection from genetic-based discrimination only pertains to insurance, not to other types of workplace discrimination.\textsuperscript{17}

2. On February 8, 2000, President Clinton signed an executive order prohibiting every federal department and agency from using genetic information in any hiring or promotion action. The order prohibits federal employers from requiring or requesting genetic tests, even for the purpose of evaluating an employee’s ability to perform his or her job. Federal employers are further prohibited from using protected genetic information to deny employees promotions or overseas posts because of a genetic predisposition for certain diseases. Strong privacy protection for genetic information used in medical treatment and research also is provided under the executive order. Obtaining or disclosing genetic information about employees or potential employees is prohibited, except when it is necessary to provide medical treatment to employees, ensure workplace health and safety, or provide occupational and health researchers access to data.\textsuperscript{18} The obvious limitation of the executive
order is that it only pertains to federal employees, leaving millions of workers without protection.

3. Although it does not directly deal with issues of genetic-based discrimination in the workplace, Title VII of the Civil Rights Act of 1964 may provide protection when genetic discrimination is based on racially or ethnically based disorders, such as in the case of *Norman-Bloodshaw v. Lawrence Berkeley Laboratory*. However, because a strong relationship between race or national origin has been established for only a few diseases, the Civil Rights Act would rarely be applicable to instances of genetic-based discrimination.\(^3\)

4. The ADA provides limited protection from genetic discrimination by employers. Although it does not specifically address genetic information, the ADA protects individuals with symptomatic genetic disabilities the same as individuals with other types of disabilities. However, the level of protection afforded those who are discriminated against because of a genetic predisposition to a disease such as cancer, Huntington’s, or cystic fibrosis, where the disability has not yet manifested (or may never be manifested), is uncertain.\(^8\)

According to Equal Employment Opportunity Commission (EEOC) Commissioner Paul Steven Miller\(^8\) in his July 20, 2000, testimony before the Senate Committee on Health, Education, Labor and Pensions, the 1995 EEOC guidance interpreting the applicability of the ADA to genetic information provides that individuals with genetic predisposition to disease are regarded as having an impairment, and are therefore covered by the ADA. In a hypothetical example described in the EEOC guidance, an employer learns that a job applicant harbors a gene that increases her risk of colon cancer. Although the applicant is healthy and may never get cancer, the conditional job offer is withdrawn because the employer fears that the applicant may contract the disease, thus affecting her productivity and insurance costs. According to the EEOC guidance that applicant would be protected by the ADA. However, the guidance does not have the same authority as a statute or regulation, nor have the courts interpreted the guidance. In fact, recent court decisions have narrowed the reach of the ADA, thereby raising questions about the extent to which the guidance would be applicable. The ADA’s ability to adequately provide protection is uncertain.\(^15\) Although none of these cases directly dealt with genetic discrimination, they cast doubt on the Supreme Court’s willingness to protect individuals with genetic markers for debilitating diseases. In his dissent in *Bragdon v. Abbott*, Chief Justice Rhenquist (joined by Justices Scalia and Thomas) specifically commented on the issue, saying that “respondent’s argument, taken to its logical extreme, would render every individual with a genetic marker for some debilitating disease disabled here and now because of some future effects.”\(^19(p.6)\)

Aside from concerns about ADA protection for genetic predisposition, there are other gaps in the act that create opportunities for abuse.\(^10,20\) The ADA does very little to restrict access
to genetic information. While the ADA prohibits an employer from making preemployment medical inquiries or examinations, a job offer may be conditioned on a pre-placement medical examination. The employer also can lawfully require disclosure of the employee’s private medical records, much of which may not be work related. Since discrimination on the basis of health status could save hundreds of thousands of dollars on a single individual’s health insurance claims, it is safe to assume that at least some employers that would have access to health information such as predisposition for a genetic disease would use that information in a discriminatory manner. \(^1\) Victims of such discriminatory actions may have a difficult time proving their claim; they may not even be aware that their genetic information has been accessed and used against them. “Some employers may have substantial economic incentives to exclude from the workforce individuals with, or who are likely to have, dependents who will incur major health expenses. The ADA may not prohibit genetic discrimination based on an employer’s desire to eliminate potentially expensive dependent health care.” \(^{18}(p.467)\)

Moreover, the ADA does not prohibit employers from using medical information in excluding or restricting employee health benefits. The legislative history of the ADA indicates that the statute is not intended to affect insurers or employers from administering and designing health plans or other insurance provisions in accordance with established underwriting techniques.\(^{13}\)

It is commonly acknowledged that the ADA does not presently provide adequate genetic privacy or discrimination protection. However, there are widely differing views on how to best provide that protection. Proposals include enactment of comprehensive genetic privacy and antidiscrimination legislation, enactment of privacy and antidiscrimination legislation that covers all types of medical information, amendment of existing laws, and a complete restructuring of the nation’s health care system to a single-payer universal health care system.\(^{21}\)

**PROPOSED LEGISLATION**

Federal legislation is necessary to provide the following basic forms of protection against genetic discrimination and abuse of genetic information: (1) legislation must apply to all insurers in both group and individual health insurance markets including self-insured employers; (2) health insurers and employers must be prohibited from genetically discriminating against insureds or employees, especially by eliminating health coverage for highest-risk individuals; (3) mandatory genetic testing should be prohibited unless there is a compelling interest; (4) unauthorized disclosure of genetic information must be prohibited, and individuals should be allowed to inspect and correct their genetic information records; and (5) legislation should provide
effective means of enforcement, including a private right of action for those harmed by abuse of genetic information.18

There have been numerous bills proposed to address medical privacy and discrimination concerns over the past few years. Some proposals deal with genetic information specifically, others also include non-genetic information. Recently, significant attention has been given to the proposed Genetic Nondiscrimination in Health Insurance and Employment Act (H.R. 2457/S. 1322). The act was discussed at a July 20, 2000 hearing before the Senate Committee on Health, Education, Labor and Pensions, on the issue of genetic discrimination.22 The act would provide a comprehensive ban on genetic discrimination in employment and would cover employers, employment agencies, labor organizations, and training programs. It would prevent discrimination in hiring, compensation, and other personnel processes, as well as prohibit employers from requiring or requesting that workers disclose predictive genetic information. Genetic testing would only be allowed for the purpose of monitoring the adverse effects of hazardous workplace exposures. Employers would be required to maintain confidentiality of predictive information, which would be disclosed only to the employee on request, or to researchers under the Common Rule.7 The legislation also would amend HIPAA to improve the limitations on collection and use of genetic information in the group market and extend them to the individual insurance market; disclosure of genetic information by health insurers to specified entities such as other insurers, employers, and information bureaus would be limited, and meaningful remedies for violations of nondiscrimination provisions would be established.22

While genetic privacy and antidiscrimination protection is clearly needed, there are significant concerns with regard to the scope and enforcement provisions of the proposed legislation, as well as its potential conflict with other laws. For example, the legislation allows claimants to circumvent the well-established screening and conciliation procedures of the EEOC simply because their claim is genetics based. It also permits victims of genetic discrimination who may be asymptomatic individuals not currently, and hopefully never, disabled to receive open-ended, uncapped damages in civil litigation beyond those damages available to currently disabled individuals whose disabilities were not genetic based. Open-ended liability in the proposed law also permits victims of genetic discrimination to receive damages beyond that of other types of discrimination claims such as race, gender, religion, national origin, and age. Also, unlike other types of discrimination claims, the proposed law is applicable to all workplaces, regardless of the size of the business or number of employees.14

Of particular concern, however, is the issue of genetic exceptionalism, which is the concept that genetic information is so fundamentally different from other health information that it must be given legal protection distinct from other forms of medical information. There is disagreement as to whether the public will be best served by legally distinguishing genetic information from other types of medical information. It is increasingly difficult to define precisely "genetic information. Genetic associations have been identified with many common disorders, and it is
often unclear whether information about such disorders is genetic information. From a medical standpoint, distinguishing genetic from other medical conditions is increasingly impossible. Various laws also have defined genetic information differently. Genetic information could be restricted to information about actual genetic material itself, such as DNA and RNA. Or it could be defined broadly to include information based on family history.

Aside from the practical difficulty of defining genetic information, there is concern about the fairness of legislation prohibiting discrimination based on genetic information but not discrimination based on non-genetic medical information. For example, it is difficult to justify different levels of legal protection for a person who, by means of a genetic test, learns he or she is a carrier of a gene that renders him or her susceptible to colon cancer as opposed to a person who has a non-genetic clinical test indicating a precancerous (non-genetic) condition that sometimes leads to colon cancer. Legislation that exclusively prohibits genetic discrimination would not cover the second individual. A compelling argument can therefore be made for drafting legislation (or amending existing laws such as HIPAA and the ADA) to prohibit discrimination based on any type of predictive medical information instead of targeting genetic information exclusively: “Genetic anti-discrimination legislation is currently based on [a] series of misconceptions . . . [that] include the presumption that a clear distinction exists between genetic and non-genetic information, tests, and diseases and the genetic exceptionalist belief that genetic information is more definitive, has greater predictive value, and is a greater threat to our privacy than is non-genetic medical information.”

CONCLUSION

Comprehensive genetic privacy and antidiscrimination legislation is urgently needed to address public concerns regarding access and use of genetic information. However, despite numerous efforts over the course of the past decade, legal protection remains inadequate. Given the increasing difficulty of distinguishing genetic from non-genetic medical information, legislation should be drafted that protects privacy interests and prohibits discrimination based on all types of predictive medical information including, but not limited to, genetic information. This will hopefully allay fears that employers and insurers will use medical records to deny jobs and health insurance.

At the present time there are several laws that provide limited protection from genetic discrimination. At the very least these laws, particularly HIPAA and the ADA, should be amended to provide expanded insurance and workplace privacy protection for all Americans, with explicit antidiscrimination provisions regarding the use of predictive medical information. Legislation also is required to safeguard patient privacy in electronic medical records beyond those covered under HIPAA.

Even if stringent antidiscrimination and medical privacy laws are enacted, it is unlikely that they will fully address public concerns about potential misuse of genetic information. Resolution of genetic privacy and discrimination issues requires examination
of the health care system's allocation of resources. Without a universal health care system, it is likely that the public will continue to have reason to fear discrimination by employers and insurers seeking to avoid the health care costs of high-risk individuals.

REFERENCES

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