



Banning Genetic Discrimination

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On February 17, 2005, the U.S. Senate passed bill S. 306, the Genetic Information Nondiscrimination Act of 2005, by a vote of 98 to 0. The previous day, the White House had announced that

“the Administration favors enactment of legislation to prohibit the improper use of genetic information in health insurance and employment [and] supports Senate passage of S. 306.” But similar legislation has been introduced in every Congress since 1995, and President George W. Bush announced his backing for a law against genetic discrimination as early as June 2001. The House of Representatives is the sticking point: knowledgeable observers consider the prospects for passage of the House equivalent of this bill to be only slightly better than they were in 2003, when the Genetic Information Nondiscrimination Act of 2003 passed the Senate by a vote of 95 to 0 but never reached the House floor. What’s going on?

Americans have been haunted by the fear of genetic discrimination since the beginnings of genetic testing more than 30 years ago. The launch of the Human Genome Project in 1990, however, brought a whole new level of scrutiny and sophistication to the consideration of genetic information. In general, the fear has focused on health insurance, since insurers have an incentive to identify and avoid clients who will cost them more money than the average client. Similar incentives apply to employers, who not only are concerned about the effects of employees’ health problems on productivity but also pay for most private health care in the United States.

Published accounts of reported

genetic discrimination in both life insurance and employment surfaced in the 1990s,¹ along with an increasing number of policy recommendations expressing concern about the potential for genetic discrimination and arguing for legislation against it.^{2,3} However, the early reports often involved allegations of discrimination on the basis of disease, rather than a genetic predisposition to disease. Subsequent studies have shown that although there is widespread concern about genetic discrimination, there are few examples of it — and no evidence that it is common.⁴

In retrospect, this finding is not surprising. A simple model would predict that a rational insurer or employer would discriminate on the basis of genetic information if the savings that could be expected from doing so outweighed the costs — in litigation, in employee satisfaction, in public relations, and in sheer adminis-

trative outlays. For the savings to be substantial, the genetic test would have to have strong predictive power, the costs associated with the genetic condition would have to be high, and the probability that it would occur while the person was covered by the insurer or employer would also have to be high. The apparent absence of genetic discrimination in health coverage and employment is probably the result of three factors: the structure of the health care financing system, state and federal legislation, and the limits of recent progress in human genetics.

Few Americans have health coverage from organizations that pick and choose whom to cover on the basis of health, using what is called medical underwriting. More than 160 million Americans receive coverage through an employer, whether their own, their spouse's or partner's, or that of another relative. Few large-scale employers ever selectively provided health coverage on the basis of an employee's medical condition; the federal Health Insurance Portability and Accountability Act of 1996 prohibited almost all employers but those in the smallest businesses from using such medical underwriting and from considering genetic risks as preexisting conditions. More than 80 million Americans are covered by federal or federal-state programs — notably, Medicare and Medicaid — that do not use medical underwriting. Very few of the more than 40 million Americans without health coverage lack it because of genetic discrimination; most simply do not qualify for governmental coverage and either cannot afford or choose not to pay for employer-provided or individually underwritten coverage. That leaves only about 10 to 15 million Amer-

icans who buy their own, individually underwritten coverage, along with perhaps an equal number of employers. Only the people in these two groups can be at risk for genetic discrimination by insurance companies. But the same health care financing system that limits the possibilities for genetic discrimination by insurers en-



courages such discrimination in employment. Employers have an incentive to reduce their future health insurance costs by not hiring or by firing people who have predictably high health care expenses, for genetic or other reasons.

The law provides a second barrier against genetic discrimination. In the past decade or so, all but 3 states have adopted laws limiting genetic discrimination for some kinds of health insurance, and about 40 states have fairly strong rules against discrimination by small employers or companies that sell individual health insurance. More than 30 states ban or limit genetic discrimination in employment.⁵ The coverage, definitions, and enforcement mechanisms vary enormously from state to state; none of the relevant laws appear to

have been defined or tested in any reported appellate-court decisions. In addition, the federal Americans with Disabilities Act, passed in 1990, may more broadly prohibit genetic discrimination in employment, depending on whether the genetic risk is considered a disability. Another federal law, the Employee Retirement Income Security Act, prohibits an employer from discriminating against current employees on the basis of their existing or projected health care expenses. Although the exact reach of these federal laws is unclear, they — along with state laws and the prospect of more stringent legislation in the future — have largely deterred insurers and employers from practicing such discrimination.

In the wake of the Human Genome Project, the third factor may strike some as surprising, but in fact there have been few recent discoveries that lend themselves to abuse in the form of genetic discrimination. Deadly, dramatic, and highly penetrant genetic diseases were identified first because they were so obvious. Fortunately (and not surprisingly, from an evolutionary perspective), such diseases are uncommon. Although many common disorders, such as asthma, type 2 diabetes mellitus, coronary artery disease, and schizophrenia, seem to have some genetic component, understanding the genetic contribution has proved to be difficult. And if a person's genetic variations contribute only a small amount to his or her risk of disease — changing it, for example, from an 8 percent lifetime risk to 12 percent or 4 percent — this genetic information will be too weak to prompt discrimination. The extent to which genetic contributions to common diseases will lead to

strong or weak predictions of future illness remains uncertain.

Although actual genetic discrimination may not be a substantial reality, several factors argue for enacting laws against it. Even if only a small fraction of the population may be at high genetic risk for serious illness and therefore for genetic discrimination that could be thought of as “rational,” protecting such people may be worthwhile. Moreover, employers and insurers sometimes act foolishly: they may discriminate in ways that are irrational but that nonetheless harm people. Perhaps most important, regardless of how likely genetic discrimination may be, the fear of it is quite real. Such fears may be deadly if they prevent people who are at risk from undergoing genetic testing, and they may have broader ill effects if they keep people from participating in research that could lead to medical advances.

If unreasonable fear were the only problem, one solution might be to educate the public about the small size of the actual risks. But current protections against genetic discrimination are complicated, confusing, and uncertain. A broad but careful federal law against

such discrimination could provide reassurance that no combination of rational arguments and state laws can offer.

Of course, all legislation has costs. Any definition of “genetic information” might end up being too broad or too narrow. Any new basis for appropriate lawsuits will inevitably provide the basis for some inappropriate claims. And the mere fact that Congress has passed legislation against genetic discrimination might have the perverse effect of convincing the public that the risk of discrimination is actually high. But although the Genetic Information Nondiscrimination Act is not perfect, the Senate has unanimously concluded correctly that it is an important step forward.

A wide range of organizations have joined the White House in supporting the bill. And as the proposed legislation has evolved over the past decade, insurers have come to tolerate it, if not to welcome it. The main opposition now comes from employer groups such as the U.S. Chamber of Commerce, and even their objections focus on details of the legislation.

If the bill gets to the floor of

the House of Representatives, it seems likely to be approved. But there is no guarantee that it will reach the floor. The House bill has been referred to three different committees; at least two of the relevant chairs have already expressed doubts about it. But the bill should be passed. Although it is not a panacea, the Genetic Information Nondiscrimination Act would be good for medicine, for science, and for the nation.

An interview with Mr. Greely can be heard at www.nejm.org.

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1. Billings PR, Kohn MA, de Cuevas M, Beckwith J, Alper JS, Natowicz MR. Genetic discrimination as a consequence of genetic testing. *Am J Hum Genet* 1992;50:476-82.
2. Rothenberg KH, Fuller B, Rothstein M, et al. Genetic information and the workplace: legislative approaches and policy challenges. *Science* 1997;275:1755-7.
3. Greely HT. Genotype discrimination: the complex case for some legislative protection. *Univ PA Law Rev* 2001;149:1483-505.
4. Hall MA, Rich SS. Laws restricting health insurers' use of genetic information: impact on genetic discrimination. *Am J Hum Genet* 2000;66:293-307.
5. National Conference of State Legislatures. Genetics laws and legislative activity. (Accessed August 11, 2005, at <http://www.ncsl.org/programs/health/genetics/charts.htm>.)

Newborn Screening — Setting Evidence-Based Policy for Protection

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In the early 1960s, a Massachusetts program for testing neonates for phenylketonuria became the first organized effort to screen newborns for genetic or metabolic disease in order to identify treatable disorders before they became symptomatic. Since that time, newborn-screening programs have expanded to include additional genetic and nongenetic conditions

and have been implemented in all U.S. states, as well as in other countries. Although the importance and clinical successes of such screening are well recognized, many issues in newborn-screening policy and practice remain controversial.^{1,2}

Newborn screening in the United States is mandated and regulated by the states, with lit-

tle direction or authority at the federal level. Consequently, there is marked state-to-state variation in the number and types of disorders that are screened for and, therefore, substantial disparities in rates of diagnosis and in the services provided to babies born in different states.^{1,2}

In the past decade, after adverse outcomes (including death)