

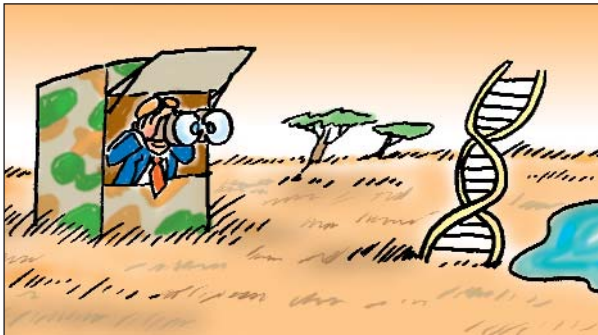
Massachusetts recently enacted a genetic testing law (12) that provides a regulatory framework for how life insurers may consider existing genetic test results in underwriting. After satisfying a two-step consent requirement, the insurer may consider test results if they are deemed "reliable," a determination that may ultimately be made by the insurance commissioner. I believe such regulation is unnecessary as long as the free market is unlikely to operate capriciously or to create a "genetic underclass."

Last fall, the Association of British Insurers, under threat of restrictive legislation, agreed to a 5-year moratorium on the use of genetic test results in underwriting life insurance policies under £500,000. I fear that this approach only tends to reinforce the perception that insurers are eager to engage in genetic discrimination. It represents a "solution" based on an untested hypothesis and impedes our ability to implement sound policy based on actual experience.

Even symbolic laws can impose a cost if they are targeted inaccurately (13). In 2002, it is certainly arguable that life insurers could absorb the additional mortality costs resulting from "genetic privacy" legislation, but such legislation would become increasingly unworkable over the course of a continuing genetics revolution. Any effort to selectively blind life insurers to the results of genetic tests already in the clinical record

will prove to be highly problematic. Individuals who advocate restrictive legislation must be able to identify the societal ill that warrants requiring insurers to operate in a regulatory minefield where any adverse underwriting decision may be attributed to consideration of routinely gathered (but protected) information.

A separate issue is whether life insurers should be allowed to order genetic tests. A genetic testing bill (14) enacted in Vermont in 1998 implicitly allows life insurers to consider existing genetic test results,



but prohibits them from ordering new tests to screen applicants for genetic risk of future disease. I believe that such a law has merit. Information asymmetry is not an issue if testing has not already been performed. Still, it is hard to imagine how insurance companies could profit from insurer-initiated genetic screening. The reality is that competitive pressure to increase sales already prompts most companies to accept, rather than avoid, marginal risks. It is increasingly likely (15, 16) that the power of genetic testing to predict mortality in

otherwise healthy adults will never be compelling enough to justify the expense of testing or the inevitable public furor.

**Conclusion.** Opinion expressed for the purpose of influencing the actions of individuals or groups is propaganda (17), not science. I concur with Greely: Those who are tempted to build support for regulation by exaggerating the importance of the problem do so "at a cost to accurate public understanding of the real significance of genetic variation and human genetics research" (18). Society is best served when discussion of ethical and social issues relating to science is conducted in the same rational and unbiased manner as the science itself.

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#### POLICY FORUM: HUMAN GENETICS

## Before It's Too Late—Addressing Fear of Genetic Information

Karen H. Rothenberg\* and Sharon F. Terry

The application of genetics to human health is poised for dramatic expansion. The draft sequencing of the human genome has already led to discoveries about some of the genetic factors contributing to heart disease, diabetes, Parkinson's disease, asthma, and other common illnesses. Before 2010, people may be able

to learn their genetic susceptibilities to common disorders, allowing for design of individualized preventive medicine through life-style changes, diet, and medical surveillance (1). We may be able to predict who will respond effectively to a particular drug therapy and who will suffer side effects.

Public support for the Human Genome Project is based on its promise for improving human health (2). However, this enthusiasm has been tempered by fear that information about our genetic make-up will make us vulnerable to discrimination by insurance companies and employers. Such

fear, whether justified or not, has already had negative effects. A recent study reported that about one-third of people expressed concern that genetic testing could cause them to lose their health insurance, and these apprehensions caused some not to participate in clinical research protocols (3). Another study found that fear about health insurance discrimination was the most frequent reason for declining genetic counseling services (4). Furthermore, surveys reflect the public's distrust. In July 2000, *Time* magazine reported that 75% of those surveyed would not want their insurers to know what diseases they are predisposed to (5). Another study found that 68% of people surveyed would not bill genetic testing to their insurance company, and 26% would use an alias to reduce the risk of insurance discrimination (6). Clearly, there are many reasons why individuals might choose not to utilize genetic services, but fear of discrimination should

K. H. Rothenberg is dean and Marjorie Cook Professor of Law, University of Maryland School of Law, Baltimore, MD 21201, USA. S. F. Terry is president, Genetic Alliance, Washington, DC 20008, USA.

\*To whom correspondence should be addressed. E-mail: krothenberg@law.umaryland.edu

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not serve as the barrier. Ironically, in attempting over the last few years to prevent future discrimination, the unintended, but unavoidable, consequence may be that fear is even more pervasive.

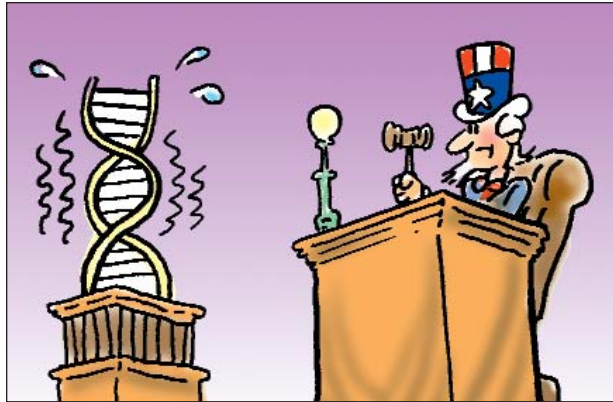
What is the basis of this fear, and is it justified? Fear of misuse of genetic information can readily be placed in the historical context of use of "genetic science" to achieve eugenic ends in the United States and in Europe in the early 1900s (7). The United States used the "genetic inferiority" of racial, ethnic, and economically disadvantaged groups as the rationale for restricting their immigration into this country (8) and for passing state laws promoting sterilization (9). Eugenics was the "scientific justification" for killing millions during the Holocaust. During the early 1970s, African Americans who were carriers for the mutation associated with sickle cell anemia were denied insurance coverage and charged higher rates (10). In 2002, a case settlement required the Burlington Northern Santa Fe Railway Company (BNSF) to pay up to \$2.2 million to employees who were secretly tested for a genetic variation purported to be associated with carpal tunnel syndrome.

Nevertheless, we have not seen widespread cases of genetic discrimination. Why? First, we do not yet have widespread utilization of genetic services. Second, individuals may not know or understand the underlying basis for an insurance or employment decision. Furthermore, without clear legal remedies, healthy individuals with a genetic predisposition may not want to risk loss of privacy for themselves and their families by going public with a discrimination claim, an even greater risk than if the discrimination claim were based on race or sex. Regardless of whether fear of genetic discrimination is based on perception or reality, we must find a way to ensure public confidence in genetics research and use of genetic information.

To date, most of the attention has focused on genetic discrimination in the context of health insurance and employment. Although adverse selection is a concern of the insurance markets, we also recognize that individuals are fearful that once access to genetic information is allowed in any context, it will be very difficult to limit its use. This concern is also at issue when government, courts, and educational institutions have access to genetic information. Just as significantly, individuals have expressed concern about the impact of sharing genetic information on family relationships. However, there is no one public policy solution that can address all these con-

cerns, particularly without a better understanding of the complexity of the issues. In the meantime, it seems prudent to try to focus our attention on the policy questions raised when addressing genetic discrimination and privacy issues in health insurance and employment (11).

*If given access to genetic information, will the insurance industry and employers use it appropriately?* It is only reasonable to be concerned that health insurers and employers may not fully understand the implications and limitations of genetic test



results and the complex relationships between genotype and phenotype. Testing positive for a mutation is often not deterministic; moreover, clinical validity and utility of most genetic tests have not yet been tracked or fully understood. For example, in the BNSF case, the employer significantly overestimated the value of a predictive genetic test.

*Should we wait and see if the problem worsens?* The promise of genetic technologies lies in the future. We cannot judge the magnitude of the potential problem from our present experience and data. Once use and sharing of genetic information has begun, it will be much more difficult to stop. Moreover, once genetic information enters databases, it will be extremely hard to remove it or prevent disclosure. When the public appreciates the extent of use of genetic information for nonmedical purposes, it will only further exacerbate fear of discrimination and loss of privacy.

*Do we need comprehensive federal legislation?* Forty-four states have passed a variety of genetic nondiscrimination and privacy laws. This patchwork of state laws, all of which have restrictions and limitations, is insufficient to provide public reassurance. Furthermore, the federal Employment Retirement and Income Security Act (ERISA) exempts self-funded plans from state insurance laws. A large proportion of the population obtains insurance through such plans and would not be protected. Al-

though the Americans with Disabilities Act (ADA) arguably protects individuals subjected to genetic discrimination in the workplace, the amount of employment protection actually provided remains limited (12).

To date, there is no comprehensive federal legislation that addresses genetic discrimination and privacy in both the insurance and employment contexts. We must establish an effective legislative framework that reduces the threat of harm by restricting access to genetic information and enforcing penalties for discrimination. Such legislation must create a level playing field, where the rules are clear and fair for all. Because the advent of predictive genetic testing does not create new illness costs (in fact, it could reduce them) and there is no evidence that adverse selection operates in health insurance, there should be no significant economic gain or loss to health insurers or employ-

ers if this information is simply declared off limits.

Last year, Senate Majority Leader Tom Daschle stated that "Millions more Americans are likely to go through what [the BNSF employees] and their families have gone through, unless Congress passes a national ban against genetic discrimination." (13). President Bush has also stated "Just as we have addressed discrimination based on race, gender, and age, we must now prevent discrimination based on genetic information." (14).

If we act now to protect genetic information and to prevent genetic discrimination, it is our hope that it will not be too late to address the public's fear and the threat of harm.

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