

Too Much Information: Fighting Against Genetic Discrimination

Save to myBoK

by Louise M. Slaughter

Genetic research may appear to offer a glimpse at our future health. Who can be trusted to use this information wisely? In this article, learn why legislation against genetic discrimination in health insurance and employment is a necessity.

As genetic research unearths the secrets of biology, it also raises concerns about privacy and discrimination. The ability to collect, disseminate, and act on genetic information can save lives as well as ruin them. Given that, genetic science must be guided by strong ethical standards and corresponding laws.

To date, however, our nation has no such laws. Instead, we are relying on a patchwork of various state efforts, as well as a smattering of federal initiatives that address specific areas of genetic science. No comprehensive federal laws or guidelines outline the permissible uses of genetic research or data. This situation persists despite the fact that scientists announced last year that they had virtually completed the map of the human genome.

Genetic discrimination provides an excellent case study of the complex ethical, legal, social, and political issues involved in the regulation of genetic science. While few, if any, parties will argue that genetic discrimination is desirable, a speedy consensus on how to ban genetic discrimination has been elusive. An analysis of the factors involved will provide valuable insights for future policy debates on other aspects of genetics and the law.

What Is Genetic Discrimination?

For the purposes of this discussion, genetic discrimination is considered to be the use of “predictive” genetic information to impact a healthy individual’s health insurance coverage or employment. In the case of insurance, this would include denying, canceling, refusing to renew, or changing the terms, premiums, or conditions of coverage. Genetic discrimination in employment would encompass decisions regarding hiring, firing, benefits, or job opportunities and advancement.

Is genetic discrimination a real threat? Consider the cases below:

*Because of numerous cases of breast cancer in her family, a healthy woman took a genetic test for breast cancer and learned that she carried the BRCA1 mutation. She decided to have a prophylactic double mastectomy and, without sharing the genetic information, petitioned her insurer to cover the procedure. When the insurance company denied her request, she revealed to them that she had the BRCA1 mutation. On learning this information, the insurer not only denied her request, but canceled her policy as well.*¹

*Terri had received outstanding job evaluations and regular, generous raises for years. While going to the doctor for allergy problems, however, she was diagnosed with Alpha1 antitrypsin deficiency, a disease that had killed her brother. She began a regimen of treatments that would keep her healthy and functional, carefully scheduling her appointments on evenings, weekends, and vacation time. When her self-insured employer learned about her condition from medical claims, however, she was told that her services were no longer needed and was asked to leave the company.*²

More than a dozen middle-aged Burlington Northern Santa Fe Railroad workers filing disability claims related to carpal tunnel syndrome were subjected to genetic tests without their knowledge or consent. The tests were searching for an extremely rare genetic condition that usually strikes young people and can sometimes include manifestations of

*carpal tunnel syndrome. The company evidently hoped to avoid paying disability claims for any workers found to carry the gene.*³

Why Do We Need Federal Legislation?

There are several reasons why it is critical that Congress ban genetic discrimination in both health insurance and employment:

- **Genetic science is not yet fully understood.** Our understanding of genetics, including the interplay between genes and the environment, is in its infancy. Much genetic information is only of limited use in determining the likelihood of illness. It is therefore virtually useless for the purpose of making decisions about insurance or employment
- **Having a predictive gene does not necessarily mean one will ever get sick.** Even if an individual carries a particular mutation, he or she could remain perfectly healthy. Alternatively, a disorder might not develop for decades. It is unfair to deny a person insurance or a job based on the fact that he or she might get sick someday
- **We all have genetic flaws.** Scientists estimate every human being has between 5 and 50 significant genetic mutations, making everyone ultimately unemployable and uninsurable
- **Relatively little medical underwriting takes place.** Health insurers readily admit that the individual market—where medical underwriting occurs—represents a very small sector of their business. The vast majority of Americans are insured through group plans, where insurance companies disregard the medical history of individual members
- **The fear of genetic discrimination is influencing Americans' healthcare decisions.** Any genetic counselor can relate stories of people who decided not to take a genetic test because they feared the results could be obtained by their insurer or employer. Still others take tests under assumed names, or pay for the procedure out-of-pocket. No one should feel compelled to deny himself or herself important medical information for fear that it will be used in a discriminatory way
- **The fear of genetic discrimination is affecting genetic research.** Many scientists engaged in genetic research are finding it increasingly difficult to recruit patients for their studies. Even when patients are told that their privacy will be rigorously protected, they remain concerned that genetic information could be released and used to undermine their interests

For all these reasons, the US needs strong, enforceable federal legislation banning genetic discrimination in health insurance and employment.

The Genetic Nondiscrimination in Health Insurance and Employment Act

I, along with Representative Connie Morella (R-MD), am sponsoring HR 602, the Genetic Nondiscrimination in Health Insurance and Employment Act. This bill represents a comprehensive solution to the problems surrounding genetic discrimination in these two areas.

With regard to health insurance discrimination, HR 602 would:

- cover all health insurance programs, including those regulated by the federal government, state-regulated plans, and the individual market
- prohibit enrollment restriction and premium adjustment on the basis of predictive genetic information or genetic services
- ban health plans and insurers from requesting or requiring that an individual take a genetic test or reveal the results of a genetic test
- prohibit health plans and insurers from pursuing or being provided information regarding predictive genetic information or the use of genetic services

With regard to employment discrimination, HR 602 would:

- cover employers, employment agencies, labor organizations, and training programs
- prevent discrimination in hiring, compensation, and other personnel processes
- prohibit employers from requiring or requesting that workers disclose predictive genetic information and allow genetic testing only to monitor the adverse effects of hazardous workplace exposures
- require predictive information possessed by employers to be confidentially maintained and disclosed only to the employee upon request, and to researchers, under the provisions of the Common Rule (a set of rules and regulations

designed to protect the rights and privileges of research participants in studies supported in part or whole by the federal government)

Identical legislation (S 318) is sponsored in the Senate by Tom Daschle (D-ND), Edward Kennedy (D-MA), Christopher Dodd (D-CT), and Tom Harkin (D-IA). In the House of Representatives, HR 602 enjoys the support of an overwhelming majority: 256 members of Congress have cosponsored the bill. In addition, more than 300 organizations concerned with health issues have endorsed this legislation, including the American Cancer Society, the American Academy of Pediatrics, the National Breast Cancer Coalition, and AHIMA.

The Opposition at Work

Over the past year, the special interest groups opposing this bill either in whole or in part have elucidated their concerns more than ever before. Some, like the Health Insurance Association of America (HIAA) remain opposed to the initiative in its entirety. HIAA argues that HIPAA is sufficient to address the rare cases of genetic discrimination that may arise. Most experts agree, however, that HIPAA has numerous loopholes that leave millions of Americans outside its protections.

Further, HIPAA fails to include provisions on important issues like preventing insurers from requesting or requiring that an individual take a genetic test, nor does it address employment discrimination. HIAA also maintains that a new genetic nondiscrimination law is unnecessary because insurers are not engaged in this practice. Unfortunately, this argument ignores the damage done by the fear of genetic discrimination, as well as the anecdotal evidence that discrimination is indeed occurring.⁴

Other parties have come forward to say that genetic discrimination legislation is necessary, but that the approach taken in HR 602 is flawed. Some of the objections raised are minor or technical, but the remainder tend to fall into three major categories:

- **Definitions:** The heart of any law is its definitions, for they determine the scope of its coverage. The authors of the Genetic Nondiscrimination in Health Insurance and Employment Act worked closely with scientists at the National Institutes of Health to create scientific definitions of terms like “genetic information” and “genetic test.” However, some opponents use popularly held definitions or subjective judgment regarding what constitutes genetic information or a genetic test
- **Enforcement and liability:** HR 602 contains stringent penalties for genetic discrimination in both health insurance or employment, including the right to go to court if one has been the victim of such discrimination. Insurers and employers alike would prefer to restrict access to the courts and to cap the penalties that could be imposed
- **Medical records privacy:** HR 602 contains modest provisions protecting the privacy of genetic information, largely in the context of limiting its availability to insurers and employers. Some object to the inclusion of these provisions, pointing out that the Department of Health and Human Services has issued comprehensive regulations governing the privacy of medical records. However, these regulations are not final: changes are expected, and no information has been released as to which portions will stand or be revised. Until we know more about the final form of the privacy regulations, it would be premature to amend HR 602

My colleagues and I intend to continue engaging in a constructive dialogue with our opponents to devise mutually acceptable solutions to these issues. In the meantime, the genetic discrimination debate foreshadows similar battles ahead on related issues. A host of other ethical and public policy issues related to genetic information and research await consideration, including the appropriate role of genetics in life, disability, and long-term care insurance. Genetic information is entwined in the ongoing debates on cloning and stem cell research. Numerous other policy questions, including the regulation of prescription drug research, the protection of research participants, and the battle against bioterrorism contain elements of genetic issues.

None of these challenges have a simple solution. Devising sensible public policies will require a national debate involving an educated and engaged public. And despite the hurdles that lie ahead, I remain confident that Congress will pass a strong genetic nondiscrimination law in the future.

A Bill's Journey Through Congress

My office is frequently contacted by doctors, patients, and researchers asking when HR 602 will be passed by Congress. Indeed, it is rather unusual for a bill with such a high level of support to be delayed by Congress in the way that HR 602 has been. A number of factors have been involved in the lack of Congressional action on this initiative.

From the time I introduced my first genetic nondiscrimination bill in 1996 until June 2001, no standing committee or subcommittee of the House of Representatives held a hearing on the issue of genetic discrimination. Even as Congress delayed, genetic science was speeding ahead without any policy framework to guide it.

Over those five years, quiet opposition to the bill came from a limited number of sources. Members of the health insurance industry expressed objections to the legislation behind the scenes. Later, members of the business lobby raised concerns about aspects of the employment nondiscrimination provisions. The committees responsible for action on the bill were being lobbied by both communities not to take any action. Even the endorsement of the Clinton administration seemed to have little impact in moving this issue onto the Congressional agenda. I labored ahead with efforts to educate members of Congress, sending informational letters and packets, sponsoring briefings writing to committees and subcommittees, and speaking on the House floor.

A number of changes that worked to the bill's benefit took place in 2001. New chairmen took the helm at the committees with jurisdiction over my bill, and they seemed more receptive to this issue than their predecessors. In June, President Bush delivered a radio address in which he called for a ban on genetic discrimination in both health insurance and employment. Perhaps most importantly, the mid-year party switch of Sen. Jim Jeffords (D-VT) threw control of the Senate to the Democrats. With that event, Sen. Tom Daschle, the sponsor of S 318, became majority leader of the Senate, while Sen. Edward Kennedy became chairman of the Committee on Health, Education, Labor, and Pensions.

Daschle's first press conference as majority leader on a legislative matter focused on the Genetic Nondiscrimination in Health Insurance and Employment Act. Shortly thereafter, Kennedy convened a hearing on the bill. These events seemed to galvanize the House committees, which quickly scheduled hearings in July. Further action was scheduled for September.

The tragic events of September 11 and later disruptions caused by the anthrax mailings threw the entire Congressional schedule into turmoil. Further action on HR 602 and S 318 was postponed until 2002, when it resumed with a February Senate hearing on genetic discrimination. Throughout this year, I will be working diligently with my colleagues to advance this legislation to the president's desk for signature.

Notes

1. Kolata, Gina. "Advent of Testing for Breast Cancer Genes Leads to Fears of Disclosure and Discrimination." *New York Times* (February 4, 1997).
2. Maudsley, Dugald. "The Terri Seargent Story: A New Era of Litigation is Dawning." *National Post* (Canada) (August 12, 2000).
3. Lewin, Tamar. "Commission Sues Railroad to End Genetic Testing in Work Injury Cases." *New York Times* (February 10, 2001).
4. "The Potential for Discrimination in Health Insurance Based on Predictive Genetic Tests." Testimony delivered by Donald A. Young, MD, on behalf of the Health Insurance Association of America before the House of Representatives Energy and Commerce Subcommittee on Commerce, Trade, and Consumer Protection, July 11, 2001. Available online at <http://membership.hiaa.org/pdfs/010711Testimony.pdf>.

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