

City Council was preparing to consider a restaurant industry–supported bill that would overturn the calorie rules.<sup>5</sup> Frieden predicted that the industry might also challenge the rules in court.

Nonetheless, calorie counts on menus may be the wave of the future. Even the savviest consumers probably need frequent reminders that trans fats aren't the only obstacles to steering a healthy course through the U.S. diet. Frieden himself is a case in point: to celebrate the approval of the trans fat regulations, the lean and

fit health commissioner ordered doughnuts for his staff from Doughnut Planet, which has eliminated trans fat from its confections. “Oh, wow, those doughnuts are delicious,” he recalled wistfully. “They were so good I couldn't stop eating them.”

**An interview with Dr. Thomas Frieden, commissioner of the New York City Department of Health, can be heard at [www.nejm.org](http://www.nejm.org).**

Dr. Okie is a contributing editor of the *Journal*.

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## Prohibiting Genetic Discrimination

Kathy L. Hudson, Ph.D.

Even before the sequencing of the human genome began in earnest, Americans started worrying about how information about their genetic makeup might be used in harmful ways, and policymakers began considering legislation to prevent misuses of genetic information. The Genetic Information Nondiscrimination Act, which would prohibit health insurers and employers from asking or requiring a person to take a genetic test and from using genetic information in setting insurance rates or making employment decisions, passed unanimously in the Senate in 2003 and again in 2005. The bill remained stalled in the House of Representatives, however, apparently because the House leadership was sympathetic to the few employer and business groups that oppose the bill. This year, with its new Democratic majority in place, Congress has taken up the bill once again.

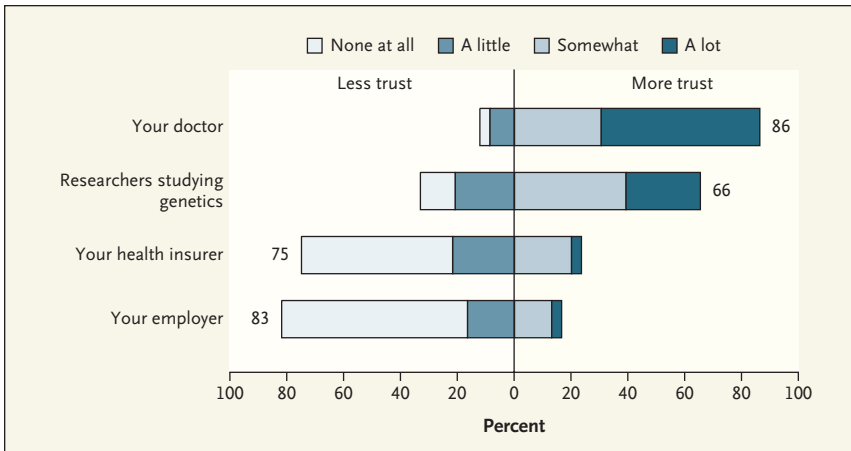
Enactment of this law would substantially enhance the current,

limited protections against the use of genetic information in health insurance and the workplace. The Health Insurance Portability and Accountability Act (HIPAA) of 1996 imposed some restrictions on the use of health-related information by group health insurers in determining eligibility for benefits and setting premiums. Congress specifically listed genetic information as protected health information and explicitly stated that a genetic risk factor for disease could not be considered a preexisting condition. Subsequently, in promulgating privacy regulations called for by HIPAA, the Department of Health and Human Services made clear that access to and disclosure of genetic information are protected. But though HIPAA restricted the ability of insurers to charge different premiums to persons within a group on the basis of genetic information, it did not limit their ability to use such information to raise the rates for the entire group. HIPAA also did

not address the use of genetic information for underwriting in the individual-insurance market.

As for the workplace, the Equal Employment Opportunity Commission has interpreted the Americans with Disabilities Act (ADA) as providing some protections against the use of genetic information by employers, but the extent of those protections is unclear and largely untested. The ADA prevents workplace discrimination based on a disability, the history of a disability, or a perceived disability. However, legal experts have concluded that additional clarification is needed to ensure that genetic information cannot be used to discriminate in employment decisions such as hiring, firing, job assignments, and promotions.<sup>1</sup>

Many states have taken steps to limit the misuse of genetic information. Currently, 35 states have laws against genetic discrimination in employment, and 47 have laws against genetic discrimina-



**Responses to the Question “How Much Do You Trust Each of the Following to Have Access to Your Genetic Test Results?”**

Data are from a survey of 1199 adults conducted from February 27 through March 4, 2007, by the Johns Hopkins Genetics and Public Policy Center ([www.dnapolicy.org](http://www.dnapolicy.org)).

tion in health insurance. However, the state-by-state approach provides an inconsistent framework, and the scope of protection provided by many state laws is extremely narrow. For example, some laws exclude chemical tests, blood tests, and routine laboratory tests from the definition of genetic tests. Given that all genetic tests are chemical tests, many are blood tests, and an increasing number are routine, many existing state laws are already outdated and provide only the illusion of protection.

Without comprehensive legal protections, the public fears genetic discrimination, and that fear has negative effects on both medical research and clinical care. Today, genetics is incorporated into almost all areas of clinical research, and scientists are proposing massive population-based studies that will enable them to identify and distinguish genetic, environmental, and lifestyle-based contributors to disease. But many potential research participants are deterred by the fear that their information could be used against them by employers or insurers.

For example, persons at risk for hereditary colon cancer who were offered genetic testing as part of a research study cited fears of genetic discrimination as their primary concern about testing.<sup>2</sup> The nondiscrimination legislation under consideration would allow researchers, for the first time, to assure participants that it is simply against the law for health insurers or employers to use genetic information to discriminate against them.

The fear factor also harms care delivery. Although the public is enthusiastic about the promise of genetic medicine for determining a person’s risk of disease or of adverse reactions to medication, growing uncertainty and fear threaten public confidence in genetic medicine and the future of the field. To keep genetic information out of their medical records and out of the hands of insurers and employers, patients sometimes pass up genetic testing that could benefit their health. Or they may go to great lengths — paying out of pocket or using assumed names — to keep the information private.<sup>3</sup> Even health

care providers are affected by these fears. In a survey of cancer-genetics specialists, more than half indicated that they would pay out of pocket rather than bill their insurance companies for genetic testing, for fear of genetic discrimination.<sup>4</sup> At a recent congressional hearing, legislators heard testimony about a woman who underwent testing for the *BRCA1* gene, using a false name to keep her results private. Ovarian cancer later developed, and her diagnosis was delayed because her genetic-test result was not in her medical record.<sup>5</sup> Although most people trust their doctors and genetic researchers, they don’t trust that health insurers or employers will not misuse their genetic information if they have access to it (see graph).

In a recent survey of nearly 1200 adults, the Johns Hopkins Genetics and Public Policy Center found that 93% believed that health insurers should not be permitted to use results from a predictive genetic test to deny or limit coverage or to charge higher prices; three quarters believed there should be a law preventing insurers from doing so. Similarly, 93% believed that employers should not be permitted to use such a test result to make hiring or promotion decisions, and more than three quarters believed there should be a law prohibiting these uses.

The new Congress is responding to the public’s concern. This year, the reintroduced Genetic Information Nondiscrimination Act (see table) has been winding through three House committees and one Senate committee. During committee consideration, several new hurdles arose. In the House, for example, employer groups opposing the bill testified

The Genetic Information Nondiscrimination Act	
What the Legislation Does	What the Legislation Does Not Do
Prohibits group and individual health insurers from using a person's genetic information in setting eligibility or premium or contribution amounts.	Does not prohibit medical underwriting based on current health status.
Prohibits health insurers from requesting or requiring that a person undergo a genetic test.	Does not mandate coverage for any particular medical tests or treatments.
Prohibits employers from using a person's genetic information in making employment decisions such as hiring, firing, job assignments, and promotions.	Does not interfere with the ability of a treating health care professional to request that a person or family member undergo a genetic test.
Prohibits employers from requesting, requiring, or purchasing genetic information about an individual employee or family member.	Does not subject employers to remedies and procedures that are different from those in other civil-rights laws, such as Title VII of the Civil Rights Act of 1964 and the Americans with Disabilities Act.
	Does not prohibit workplace collection of genetic information for genetic monitoring programs, employer-sponsored wellness programs, administration of federal and state family and medical-leave laws, and in certain cases of inadvertent acquisition of information. However, this genetic information may not be used or disclosed by the employer.

that it would stifle the provision of medical care, despite its clear statement that it does not restrict the ability of health care providers to recommend genetic testing for patients or to use test results in providing clinical care. Health insurers, meanwhile, sought additional language stating that the bill does not restrict the ability of health insurance plans to provide information about genetic tests to patients and providers, even though the bill does nothing to restrict communication about genetic tests. Insurers also wanted to be able to “recommend” tests to patients, but so far, legislators have recognized that this is the role of health care providers, not insurers.

Some members of one House committee attempted, unsuccessfully, to modify the bill's definitions of “genetic test” and “genetic information” in ways that would substantially narrow or

even obliterate the bill's protections. The definitions in the bill were carefully crafted by geneticists, physicians, legal scholars, and patients, in consultation with insurers and employers, to protect a patient's genetic information but to avoid encompassing information about clinical signs or symptoms of disease.

Finally, the Catholic Church and others raised concerns that the genetic information of fetuses and in vitro embryos might be left “unprotected.” Given that in all 50 states, health insurers must permit newborns to be added to an insurance policy without any exclusions for preexisting conditions, this last-minute objection seems to have been driven more by ideology than by practical concerns. But the language that was drafted was not opposed by either “prochoice” or “prolife” groups, and it left the bill essentially undisturbed.

The final chapter has not yet been written. On June 23, 2001, President Bush said that “Genetic discrimination is unfair to workers and their families. . . . To deny employment or insurance to a healthy person based only on a predisposition violates our country's belief in equal treatment and individual merit.” Now, with congressional passage of vital protections against genetic discrimination nearly certain, President Bush should finally get a chance to sign a bill whose time has come.

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