

GOVERNMENT & MEDICINE


After 13 years, Congress OKs genetic bias ban

The bill would bar health insurers from basing eligibility or premiums on genetic information.

By [Dave Hansen](#), AMNews Staff. May 19, 2008.

Washington -- House and Senate passage of legislation to prohibit genetic discrimination has moved the federal government closer to eliminating a major barrier to these screenings -- patients' fear, physicians say.

"Genetic testing holds great promise for improving public health, and patients must be able to trust that their genetic information will be protected from inappropriate and discriminatory uses," said American Medical Association Board of Trustees Chair Edward L. Langston, MD. "This bill will allow patients to take advantage of scientific advances in genetics, such as screenings and therapies, without worrying that their personal health information could be used against them by insurers or employers."

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The Genetic Information Nondiscrimination Act, which President Bush is expected to sign, would ban health insurance companies from basing eligibility or premiums on genetic information. It also would prohibit employers from hiring, firing, promoting or placing employees on the

basis of genetic information.

"This is a great gift to all Americans," said Francis S. Collins, MD, PhD, director of the National Human Genome Research Institute. "Since each of us has dozens of genetic variations that may put us at risk for disease, we all would have had a reason to be concerned about the possible misuse of genetic information."

Patients definitely fear the consequences of genetic tests, said Edward R. B. McCabe, MD, PhD, physician-in-chief at Mattel Children's Hospital at the University of California, Los Angeles and professor and executive chair of its Dept. of Pediatrics.

"People talk to me about getting tested under pseudonyms and not reporting it to their insurance company or employers for fear they would be discriminated against," said Dr. McCabe, who also is a director of the UCLA Center for Society, the Individual and Genetics.

41 states prohibit genetic discrimination.

A 2006 poll by Cogent Research found that 66% of respondents reported having concerns about how their genetic information would be stored and who could access it, and 85% said that employers would discriminate on the basis of genetic information without a law.

Removing the threat of genetic discrimination would benefit physicians as well. The legislation would simplify the regulatory landscape, currently a confusing patchwork of state and federal regulations, Dr. McCabe said.

Forty-one states prohibit genetic discrimination, said Joann A. Boughman, PhD, executive vice president of the American Society of Human Genetics. Some states, however, address discrimination only by health insurers, while others apply only to employers, she stated. The congressional bill would not preempt stronger state laws.

Federal employment law prohibits genetic discrimination, but it does not apply to the private sector. The Health Insurance Portability and Accountability Act bans denial of coverage on the basis of genetic information, but only in the group insurance market.

HIPAA also bars health plans from raising the premium of one member in a group based on that person's genetic information. It does not prohibit raising the premiums of all group members based on one person's genetic profile.

A long time coming

The bill's overwhelming passage -- 95-0 in the Senate on April 24 and 414-1 in the House on May 1 -- comes after 13 years of effort by its supporters. The legislation was a low priority in Congress when it was first introduced in 1995 because few genetic tests existed then, Dr. Boughman said. The sequencing of the human genome and the explosion of genetic testing has made genetic discrimination more relevant, she added.

Genetic tests for about 300 diseases were available in 1995, compared with screenings for more than 1,500 conditions today, according to GeneTests, a Seattle genetic information organization funded by the National Institutes of Health.

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The legislation also was delayed by Sen. Tom Coburn, MD (R, Okla.), who placed a legislative hold on it. Dr. Coburn supports genetic nondiscrimination but was concerned that earlier bill versions would have subjected self-insured companies to dual lawsuits for the same incident -- once as the employer and again as the health insurer, said his spokesman, Don Tatro. The senator withdrew his hold after negotiating changes to prevent this, Tatro said.

Rep. Ron Paul, MD (R, Texas), was the only lawmaker to vote against the bill. The federal government has a poor record of defending personal privacy, he explained. The best way to address discrimination is to defer to states and local communities, which can tailor laws to specific populations, he added.

The U.S. Chamber of Commerce also opposed the legislation. It would allow up to \$300,000 in punitive damages, an excessive amount, said Michael Eastman, the group's executive director of labor policy.

The Bush Administration had not issued a statement of administration policy on the bill at press time in early May. But Bush supports prohibiting the improper use of genetic information in employment and health insurance, said Office of Management and Budget spokeswoman Corinne Hirsch. He likely will sign the bill, she said.

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ADDITIONAL INFORMATION:**Genetic testing options going up**

The number of diseases for which genetic tests are available has skyrocketed.

	Diseases with available genetic tests
1993	111
1994	225
1995	303
1996	420
1997	485
1998	625
1999	704
2000	768
2001	760
2002	845
2003	917
2004	1,071
2005	1,237
2006	1,341
2007	1,497
2008 (to early May)	1,551

Source: GeneTests, an information source funded by the National Institutes of Health

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AMA on genetics and molecular medicine (www.ama-assn.org/go/genetics)

GeneTests, a medical genetics information resource funded by the National Institutes of Health (www.genetests.org)

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