



# Congress Passes Bill to Ban Discrimination Based on Individuals' Genetic Makeup

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**I**N A MOVE TO PROTECT INDIVIDUALS from health insurance or employment discrimination based on their genetic information, both the House and Senate have overwhelmingly passed the Genetic Information Nondiscrimination Act (GINA). The protections provided by the act are meant to encourage US individuals to obtain genetic testing as part of their medical care without fear of discrimination.

The progress of GINA's passage can be tracked at <http://www.genome.gov/24519851>.

At press time, President Bush, who was among those who urged Congress to pass such legislation, was expected to sign the bill into law. "We want medical research to go forward without an individual fearing of personal discrimination," Bush said during a roundtable discussion at the National Institutes of Health (NIH) last year.

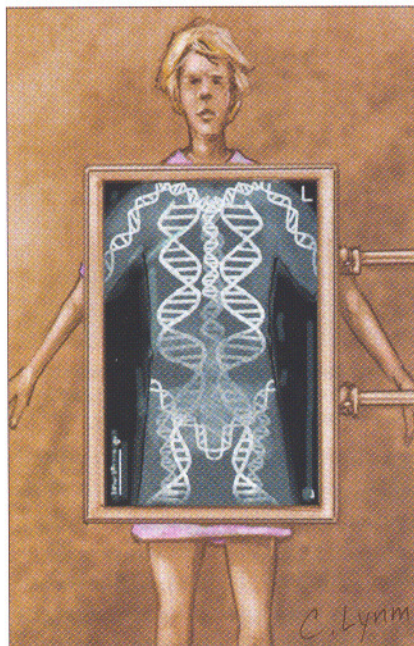
## SUPPORT FOR GINA

Legislation to protect against genetic discrimination was first introduced 13 years ago by Rep Louise Slaughter (D, NY). Since that time, researchers, clinicians, and patient advocacy groups have been pushing for safeguards against abuse of individuals' genetic information.

"While it was a really onerous process, I'm very pleased with the final product," said Sharon Terry, president and CEO of Genetic Alliance, a Washington, DC-based coalition of more than 600 disease-specific advocacy organizations.

In testimony to a House subcommittee last year, National Human Genome Research Institute Director Francis Col-

lins, MD, PhD, pointed to examples of public concern over the possible misuse of genetic information by health insurers or employers. For example, an NIH study of families at risk for hereditary nonpolyposis colorectal cancer



Congress has passed legislation that bans the use of genetic information in decisions about a person's health insurance or employment.

found that losing health insurance if genetic test results were made known was the primary concern expressed by participants regarding testing.

Collins also noted that a survey of the personal attitudes of cancer genetics specialists showed that the majority of respondents would not submit claims for cancer genetic tests for themselves to their own insurers due to fear of discrimination.

Collins and other scientists have said that fear of genetic discrimination could

also slow medical research and clinical advances. "It used to be that most genetics research was in families with a known hereditary condition or in relatively small cohorts of affected and unaffected people," said Kathy Hudson, PhD, director of the Johns Hopkins University's Genetics and Public Policy Center in Washington, DC. "Now we'll be able to propose really large-scale population-based studies that look at the multitudes of weak genetic contributors to a common disease and their interaction with environmental and lifestyle factors," she explained.

## NEW LEGAL PROTECTIONS

Under GINA, health insurers will be barred from rejecting coverage or raising premiums for healthy individuals based on personal or familial genetic predispositions to diseases such as cancer or diabetes. Employers also cannot discriminate based on such predispositions.

Several cases of genetic bias by employers have been documented in the past. When Slaughter reintroduced GINA in 2007, she noted that throughout the 1970s, many blacks were denied jobs, educational opportunities, and insurance based on their carrier status for sickle cell anemia. More recently, Lawrence Berkeley National Laboratory in Berkeley, Calif, and the Burlington Northern Santa Fe Railroad performed genetic tests on employees without their knowledge or consent.

"Once the law is in effect, people can rest assured that they can feel free to start using genetic tests to manage their health and can be involved in clinical trials without worrying about discrimination," said Terry. □