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## Congress Passes Bill Barring Genetic Discrimination Action culminates more than a dozen years of legislative haggling

By Lisa Stein

The House today passed a measure by a whopping 414-to-1 margin that would prohibit health insurers from canceling or denying coverage or hiking premiums based on a genetic predisposition to a specific disease. The legislation, the Genetic Information Nondiscrimination Act (GINA), also bars employers from using genetic information to hire, fire, promote or make any other employment-related decisions.

Rep. Ron Paul (R-Tex.) was the lone dissenter.

The measure, which unanimously [passed the Senate](#) last week, now goes to President Bush, who is expected to sign it into law.

"Since no one is born with perfect genes, we are all potential victims of genetic discrimination. This legislation marks the beginning of a new era in health care where a person's genetic information can no longer be used against them," bill sponsor Rep. Louise Slaughter (D-N.Y.) said after the legislation sailed through the House. "By prohibiting the improper use of genetic information, Americans will be encouraged to take advantage of the tremendous life-altering potential of genetic research."

Slaughter, a microbiologist with a Master's degree in Public Health, introduced the first genetic antidiscrimination legislation 13 years ago.

Physicians now have access to more than 1,000 genetic tests that diagnose or assess the risk of developing potentially life-threatening diseases, including breast cancer, diabetes, heart disease and Parkinson's.

Consumer advocates hailed the passage of the package, which they say will close gaps in state laws and encourage Americans to take advantage of potentially lifesaving genetic testing that they may now shun out of fear of being sacked or denied health benefits.

"With the long-awaited federal passage of GINA, researchers and clinicians can now actively encourage Americans to participate in clinical trials without the fear of genetic discrimination," said Joann Boughman, executive vice president of the American Society of Human Genetics (ASHG). "Furthermore, under the federal protection provided by GINA, health care practitioners will be able to recommend appropriate genetic testing and screening procedures unencumbered by the fear of discrimination based upon the results."

In the 1970s, many blacks were denied jobs and insurance coverage because they carried a gene for sickle-cell anemia, including those who lacked the two copies of a mutation necessary to get sick.

In 1998, it was revealed that Lawrence Livermore National Laboratory in Berkeley, Calif., had secretly tested employees from the 1960s to 1993 for sickle-cell anemia, syphilis and pregnancy without their knowledge or consent (they were told that they were undergoing routine cholesterol screening). In 2002, the Burlington Northern Santa Fe Railway company paid three dozen employees \$2.2 million to settle a lawsuit they had filed charging that the company had genetically tested them without their knowledge after they submitted work-related injury claims.

"This bill will allow every citizen and their physicians to benefit and participate in the progress the gene therapies provide for all of us in early treatment and the prevention of countless afflictions while maintaining their essential insurance coverage," Rep. Steve Kagen, D-Wis., a physician, said in support of H.R. 493 during the debate.

"Perhaps in the near future, I'll be able to rise here on the House floor and ask that we support legislation to bring an end to all forms of discrimination in health care," he added. "After all, our constitutional rights protect us against discrimination and should be applied to the area of health care throughout the industry – not just genetic information, not just skin color, not just body chemistry or the content and structure of one's bones – but to everything in the human condition and every pre-existing condition. Let's begin to put discrimination where it belongs – in the past."

