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Bill prohibits bias based on genes

RESULTS OF NEW TESTING WILL GET PROTECTION

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New York Times

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A bill that would prohibit discrimination by health insurers and employers based on the information that people carry in their genes won final approval in Congress on Thursday by an overwhelming vote.

The legislation, which President Bush has indicated he will sign, speaks both to the mounting hope placed in genetic research to greatly improve health care and the fear of a dystopia in which people's genetic information could be used against them. On the House floor Thursday, Democrats and Republicans alike cited anecdotes and polls illustrating that people feel they should not be penalized for what is in their genes.

"People know we all have bad genes, and we are all potential victims of genetic discrimination," said Rep. Louise Slaughter, D-N.Y., who was a key sponsor of the bill, which passed the House on Thursday by a 414-1 vote, and the Senate by 95-0 a week earlier.

Still, some experts said people still should be cautious with their genetic information. The bill leaves open the ability for insurance companies to ask customers to take genetic tests that they believe could lead to preventive therapies.

Doctors say a fear of discrimination on the part of patients has prevented thousands at risk of genetic

disease from taking advantage of tests that might help them make better health care choices. Some patients worry they may be denied jobs or face higher insurance premiums if a genetic predisposition to disease shows up in their medical records.

Many who do learn that they are at higher risk for a disease choose not to ask their insurance companies to cover the costs of the genetic test, to keep the information secret. Some try to persuade medical professionals not to enter the test results in their health records; others keep the information from their doctors.

If the bill is signed into law, many more people are expected to take advantage of genetic testing and to participate in genetic research.

The measure did not always have such overwhelming support. Similar legislation had foundered for more than a decade in the face of opposition from employers and insurers and skepticism from lawmakers over its necessity: virtually no cases of genetic discrimination have ever been documented.

But with the mapping of the human genome and the rapid discovery of genetic variants that contribute to a risk of common diseases like breast cancer, colon cancer, diabetes and heart disease, the number of people who might benefit from learning what risks lie in their own genes is growing quickly.

Sen. Tom Coburn, R-Okla., who had blocked the bill for months, agreed to let it go forward after language was included to protect employers from lawsuits that stem solely from insurance company violations of the bill.

The U.S. Chamber of Commerce still opposed it, arguing that the fines were excessive and that its

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limits on the collection of medical information would complicate even routine practices, like recording a request by an employee to take a leave to take care of a parent with cancer.

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