



US House Passes Genetic Discrimination Bill

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By a GenomeWeb staff reporter

This article has been updated to include additional comments.

NEW YORK (GenomeWeb News) – A little less than a week after its passage by the US Senate, the Genetic Information Nondiscrimination Act has been passed by the US House of Representatives by a vote of 414 to 1.

The bill is the closest it has ever come to being signed into law after being considered in various iterations by both chambers of Congress over the past decade. GINA, which would protect Americans from discrimination based on information from genetic tests, had previously passed in the House twice before — most recently last year, when the vote was 420 to 3 in favor of its passage.

The lone congressman voting against the bill was Representative and Republican Party candidate for president Ron Paul (R – Tex.). Congressman Paul's office was not available at deadline for a statement about the bill.

"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," Joann Boughman, executive vice president of the American Society of Human Genetics, said in a statement. "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."

As reported last Friday by *GenomeWeb Daily News*, the US Senate [unanimously passed](#) the bill after senators agreed to compromises that had held up the bill since last summer.

The legislation protects consumers against adverse coverage or pricing decisions by insurance companies based on a person's genetic predisposition toward a disease. It also ensures that employers cannot make adverse employment decisions based on what is in a person's genetic code. In addition, insurers and employers are not allowed under the law to request or demand a genetic test.

"By prohibiting the improper use of genetic information, Americans will be encouraged to take advantage of the tremendous life altering potential of genetic research," Representative Louise Slaughter (D – NY), said in a statement Thursday.

Slaughter wrote the bill and championed it for over a decade, received her bachelor's degree in microbiology and has a master's degree in public health.

At a bioethics conference made in Cleveland yesterday the news of the passage of the bill was met with little surprise, possibly because many of the attendees were not aware that it had gone back to the House before going on to the White House.

Among the pro-GINA crowd at the Translating ELSI Genomics meeting there was no celebration beyond a few claps when Jeff Botkin, a pediatrics professor and medical ethicist at the University of Utah's School of Medicine, interjected into a meeting about ethical research practices of pediatric genetic testing to say that the bill had just passed the House.

Botkin said that because the fear that insurance companies would use information from genetic tests against people is

among the most common reasons people give for not wanting to participate in genetic studies, this law should help to remove that barrier.

Senator Edward Kennedy (D – Mass.), who co-sponsored the Senate bill and who helped to work out the compromises that gave the bill new life last week, said the legislation "paves the way for every American to benefit from the vast potential of this new age of genetic information."

Kennedy also said he hopes President George W. Bush "will sign it immediately and open the door to a new era of medical progress."

The senior senator may soon get his wish. The White house has said in several policy statements in recent years that it supports a bill barring discrimination based on genetic information, and an aide for Senator Tom Coburn (R – Okla.) told *GenomeWeb Daily News* that the president's earlier concerns about the bill have been addressed in this draft and that GINA is now a done deal.

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