



Multiplexing

Bush Signs Genetic Nondiscrimination Bill Into Law

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By a GenomeWeb staff reporter

NEW YORK (GenomeWeb News) – Early this afternoon, US President George W. Bush signed into law the Genetic Information Nondiscrimination Act, making it illegal to discriminate on matters of employment and health insurance in the US based on genetic information.

A law that was more than a decade in the making, GINA was signed today by the president after passing in Congress with near unanimous support in both houses after legislators managed to [reach agreements](#) on certain language that had previously stopped the bill in the Senate.

Before signing GINA in the Oval Office, President Bush said “it protects our citizens from having genetic information misused, and this bill does so without undermining the basic premise of the insurance industry.”

Bush also took a moment to “pay homage” to the members of Congress who worked on the bill, “but also to Senator Ted Kennedy, who has worked for over a decade to get this piece of legislation to a president’s desk.”

Kennedy (D – Mass.) was diagnosed with a brain tumor earlier this week and is currently in his home state on leave from the Senate.

The law was envisioned to protect an individual’s civil rights against discrimination as genetics technologies become more commonplace. That bill was particularly forward-looking over a decade ago when it was proposed by Congresswoman Louise Slaughter (D – NY) and backed by Senator Olympia Snowe (R – Maine).

“This is a tremendous victory for every American not born with perfect genes – which means it’s a victory for every single one us,” Slaughter said in a statement today, adding that “we are all potential victims of genetic discrimination.”

“Up until now, our laws have not kept pace with emerging technology, and doubts about the misuse of genetic information are preventing Americans from participating in tests that could improve their long-term health,” Snowe said in a statement.

“Americans have been waiting a long time for this bill, but the wait has been worth it,” Johns Hopkins University’s Genetics and Public Policy Center Director Kathy Hudson said in a statement. “Our challenge now is to make sure that doctors and patients are aware of these new protections so that fear of discrimination never again stands in the way of a decision to take a potentially life-saving genetic test.”

The law will not be implemented immediately. The health insurance protections are expected to begin in about a year and the employment rules are to take full effect in about a year and a half, according to Genetic Alliance.

Sharon Terry, Genetic Alliance’s CEO, said that it “is now our responsibility to make sure the public knows that these new protections are in place.” Terry said that “the promise of genetic testing and disease management and prevention can be realized more fully.”

“Once this legislation has taken effect, clinicians will be able to order genetic tests for patients and their families in a manner that ensures the full realization of the advantages of personalized medicine, while also easing patients’ concerns about the risk of genetic discrimination by insurance companies and employers based on this data,” said Joann Boughman, executive VP of the American Society of Human Genetics.

The law prohibits group health insurance plans and issuers from basing determinations about premiums or contributions on an individual's genetic information. These companies may not request, require, or buy the results of genetic tests, and they are prohibited from disclosing genetic information.

Those who issue Medigap policies also will not be allowed to make conditions about eligibility based on genetic information.

Under the law, employers will not be allowed to use genetic information in considerations regarding hiring and firing, or in drafting conditions of employment. Like insurance companies, employers will not be allowed to request, require, or buy an individual's genetic information, and the law prohibits disclosing private genetic information. The law extends to employment agencies and to labor organizations.

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