

Genetic Information Nondiscrimination Act clears Senate

April 24 2008

The Senate passed the Genetic Information Nondiscrimination Act (GINA) on April 24, approving by unanimous consent an amended version of H.R. 493, which passed the House April 25, 2007 by a vote of 420-3. The House is expected to take up the measure again quickly before sending it to President Bush to sign the measure into law.

"After a very long wait, Americans can now be confident that their genetic information cannot be used by health insurers or employers in harmful or hurtful ways," says Kathy Hudson, director of the Genetics and Public Policy Center, established at Johns Hopkins University by The Pew Charitable Trusts. "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 genetic test that could save a life."

The legislation, when signed, will fulfill the longstanding agreement among American citizens and politicians that protection from genetic discrimination should be clear and consistent, Hudson explains. Until now, individuals' genetic information has been protected only by a largely untested patchwork of state and federal regulations. Ninety-two percent of Americans are concerned that results of a genetic test could be used in ways that are harmful to the person.

Moreover, scientists can now in good conscience tell patients and research participants that their genetic information is protected against misuse by health insurers and employers. Linking gene variants to health

outcomes often requires studies involving large numbers of people, but scientists report that potential subjects are deterred by the fear that their information could be used against them by employers or insurers. In a survey of more than 4000 people conducted earlier this year, for example, the Center found that when considering whether or not to participate in genetics research, 93 percent of respondents said it was important that it be “illegal for insurers or employers to get my information.”

In addition to impeding research that would help to bring about the much-heralded era of personalized medicine, the threat of discrimination affects individual patients who could benefit from genetic testing have sometimes foregone it out of concern over possible repercussions. When people opt not to be tested, they lose the opportunity to seek monitoring and preventive care to avoid conditions for which they are at higher risk. Passage of GINA means that Americans will no longer have to make the trade-off between genetic privacy and appropriate health care.

The Senate unanimously passed versions of GINA in 2003 and 2005, but in both years the bill stalled in committee in the House. Last year, however, the House passed the measure quickly and today, the Senate for a third time expressed its commitment to nondiscrimination.

Source: Genetics & Public Policy Center, Johns Hopkins University

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