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Author of Genetic Information Nondiscrimination Act,
Applauds Bill's Passage in Senate

Passage by House
and President's Signature Expected Shortly

Washington, DC – Congresswoman
Louise M. Slaughter (D-NY-28), Chairwoman of the House Committee on Rules,
today applauds passage of the Genetic Information Nondiscrimination Act by
the Senate. Rep. Slaughter, a
microbiologist with a Masters in Public Health, authored and first introduced genetic antidiscrimination legislation, thirteen
years ago.

The
Genetic Information Nondiscrimination Act (GINA) would
prevent health insurers from canceling, denying, refusing to renew,
or changing the terms or premiums of coverage based solely on a genetic
predisposition toward a specific disease. The legislation also bars employers

from using individual's genetic information when making hiring, firing, promotion, and other employment-related decisions.

"Since no one is born with perfect genes, each one of us is a potential victim of genetic discrimination," said Rep. Slaughter. "By prohibiting the improper use of genetic information, this bill encourages Americans to undergo the testing necessary for early treatment and prevention of genetic-based diseases. "

"This legislation not only will stamp out a form of discrimination, but will allow us to realize the tremendous life-saving and life-altering potential of genetic research," Slaughter continued. "This will usher in a whole new era of health care. These important protections will enable the scientific and medical communities to make the critical medical breakthroughs of the twenty-first century."

BACKGROUND

Rep. Slaughter introduced the first genetic antidiscrimination bill in 1995. However, it took the new Democratic Congress to make protection of genetic information a national priority.

During the 110th Congress, Rep. Slaughter, along with Rep. Biggert (R-IL-13), Rep. Eshoo (D-CA-14), and Rep. Walden (R-OR-2), introduced H.R. 493, the Genetic Information Nondiscrimination Act on January 16, 2007. In April 2007, the House passed H.R. 493 by an overwhelming vote of 420 -3. The House reaffirmed its support on March 5, 2008 when it passed the Paul Wellstone Mental Health Parity Act, which included GINA within the legislation.

The Senate had passed this bill unanimously twice in previous Congresses. However, during the 110th Congress, there was a hold placed on the bill in the Senate. The yearlong hold was released after lengthy negotiations ended successfully last week.

The measure must now be approved by the House once again before being sent to the President for signature. Given the House's previous support for Rep. Slaughter's legislation, passage is expected.

Support in the White House: On April 25, 2007, the Bush Administration issued a Statement of Administration Policy (SAP) in support of H.R. 493.

Historical Precedents Indicate Need for Legislation: In the 1970s, many African-Americans were denied

jobs, educational opportunities, and insurance based on their carrier status for sickle cell anemia, despite the fact that a carrier lacked the two copies of a mutation necessary to get sick. In 1998, Lawrence Livermore Laboratories in Berkeley was found to have been performing tests for syphilis, pregnancy, and sickle cell on employees without their knowledge or consent for years. In 2000, the Burlington Northern Santa Fe Railroad performed genetic tests on employees without their knowledge or consent.

Broad

Public Support: In 2002, 85 percent of those surveyed by the Genetics and Public Policy Center at Johns Hopkins University did not want employers to have access to their genetic information. By 2004, that number had risen to 92 percent. In 2002, 68 percent of those surveyed said their genetic information should be kept private from health insurers. By 2004, it had increased to 80 percent.

Broad

Support Among Health Care Professionals: In one survey of genetic counselors, 108 out of 159 indicated that they would not submit charges for a genetic test to their insurance companies primarily because of the fear of discrimination. Twenty-five percent responded that they would use an alias to obtain a genetic test so as to reduce the risk of discrimination and maximize confidentiality. 60 percent indicated they would not share the information with a colleague, because of the need for privacy and fear of job discrimination.

Over 200 health, medical, and scientific organizations have endorsed GINA.

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