

**FOR IMMEDIATE RELEASE**

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**Rep. Slaughter and Biggert Announce Bi-Partisan Genetic Non-Discrimination Legislation**

**Washington, DC** - Rep. Louise M. Slaughter (D-NY-28), Chairwoman of the House Rules Committee, was today joined by Rep. Judy Biggert (R-IL-13) and Sharon F. Terry, Chair of the Coalition for Genetic Fairness, in announcing the reintroduction in the House of the Genetic Information Nondiscrimination Act (GINA).

**“This bill is the culmination of a bipartisan effort to prohibit the improper use of genetic information in workforce and insurance decisions,”** Rep. Slaughter said. **“In the 12 years since I first introduced genetic nondiscrimination legislation, the need for it has grown exponentially. Scientific research has advanced so quickly that we cannot afford to wait any longer. This bill will allow us to preserve America's health and protect our scientific edge, all while defending the privacy of our citizens.”**

**"We will never unlock the great promise of the Human Genome Project if Americans are too paranoid to get genetic testing,"** said Rep. Biggert, a chief sponsor of the legislation in the 109th Congress.

**□ "Without the protections offered by H.R. 493, these fears will persist, research at NIH will slow, and Americans will never realize the benefits of gene-based medicines."**

**"This bill is about our children, our future, and ensuring that Americans cannot be discriminated against in health insurance and employment decisions,"** said Sharon Terry.

**"As an advocate and as the Chair of the Coalition for Genetic Fairness, I understand the promise of genetic medicine and am appalled by the experiences of the many individuals and families who have experienced genetic discrimination."**

**"Congresswoman Slaughter, Congresswoman Biggert, Congresswoman Eshoo, and Congressman Walden demonstrate robust vision and courage to introduce legislation that will make it possible for people to benefit from new genetic tests and technologies,"** she added.

## **BACKGROUND**

H.R. 493, the Genetic Information nondiscrimination Act, or GINA, is a bi-partisan bill co-sponsored by over 150 Members of Congress. The legislation was introduced in the House by Rep. Slaughter, Rep. Biggert, Rep. Anna Eshoo (D-CA-14), and Rep. Greg Walden (R-OR-2) on Tuesday, January 16th.

GINA makes it illegal for group health plans and health insurers to deny coverage to a healthy individual or charge him or her higher premiums based solely on a genetic predisposition to a specific disease. The legislation also bars employers from using individuals' genetic information when making hiring, firing, job placement or promotion decisions.

**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 Healthcare 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.

**Support in the White House and Senate:** On Wednesday, January 17th, the President once again indicated his support for legislation to prevent genetic discrimination by insurance companies. In the 109th Congress, the Administration issued an official Statement of Administration Policy (SAP) in support of GINA. Furthermore, the Senate has already passed this bill unanimously twice in recent years.

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