

April 25, 2007 - House Passes Genetic Non-Discrimination Bill Sponsored by Reps. Slaughter & Biggert

Washington, DC - Rep. Louise M. Slaughter (D-NY-28), Chairwoman of the House Rules Committee, and Rep. Judy Biggert (R-IL-13) today applauded passage of the Genetic Information Non-discrimination Act (H.R. 493) in the House of Representatives. The bill, known as GINA and authored by Rep. Slaughter, was first introduced by the Congresswoman twelve years ago. The passage of GINA comes after over a decade of fighting for federal legislation to protect Americans from genetic discrimination.

FOR IMMEDIATE RELEASE

Wednesday, April 25, 2007

House of Representatives Passes Genetic Non-Discrimination Bill Sponsored by Reps. Slaughter and Biggert
Bill Will Prohibit Improper Use of Genetic Information in Workforce and Insurance Decisions

Washington, DC - Rep. Louise M. Slaughter (D-NY-28), Chairwoman of the House Rules Committee, and Rep. Judy Biggert (R-IL-13) today applauded passage of the Genetic Information Non-discrimination Act (H.R. 493) in the House of Representatives. The bill, known as GINA and authored by Rep. Slaughter, was first introduced by the Congresswoman twelve years ago. The passage of GINA comes after over a decade of fighting for federal legislation to protect Americans from genetic discrimination.

"I am extremely pleased to see this historic bill pass the House of Representatives with such overwhelming support," said Rep. Slaughter. "For years, we've held up genetic research because people were afraid that their genetic information would be used against them. This legislation addresses those fears by prohibiting the improper use of genetic information by a person's employer or insurer."

"GINA will do more than stamp out a new form of discrimination. It will also help our country to be a leader in a field of scientific research that holds as much promise as any other in history," continued Slaughter. "It will allow us to realize the tremendous potential of genetic research without jeopardizing one of the most fundamental privacies that can be imagined. GINA will encourage Americans to seek out preventative health care and participate in clinical trials critical to

finding cures for some of our most deadly genetic-based diseases."

"We will never unlock the great promise of the Human Genome Project if

Americans are too paranoid to get genetic testing," said Rep. Biggert. "Without the protections offered by H.R. 493, these fears will persist, research at National Institutes of Health (NIH) will slow, and Americans will never realize the benefits and health care savings of gene-based medicines."

The Genetic Information Non-discrimination Act 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.

BACKGROUND

H.R. 493, the Genetic Information Non-discrimination Act, or GINA, is a bi-partisan bill co-sponsored by over 220 Members of Congress. The legislation was introduced in the House by Rep. Slaughter, Rep. Biggert (R-IL-13), Rep. Anna Eshoo (D-CA-14), and Rep. Greg Walden (R-OR-2) on Tuesday, January 16th.

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

Support in the White House and Senate: On Wednesday, January 17th, 2007 the President once again indicated his support for legislation to prevent genetic discrimination by insurance companies. And today, the Administration issued an official Statement of Administration Policy (SAP) in support of GINA. The Senate has already passed this bill unanimously twice in recent years.

The complete text of Rep. Slaughter's remarks, as prepared, as included below:

THE HONORABLE LOUISE M. SLAUGHTER

THE GENETIC INFORMATION NONDISCRIMINATION ACT

APRIL 25, 2007

M. Speaker,

Today, it is with great pride that I rise in support of the Genetic Information Nondiscrimination Act, a bill well over a decade in the making. With the passage of this bill, Congress will stand up for the future health of both our citizens and one of medicine's most promising fields: genetic research.

GINA is the culmination of a bipartisan effort to prevent the improper use of genetic information in workforce and insurance decisions.

This problem is no longer simply the work of science fiction writers.

There have been many instances of genetic discrimination: from a woman who was fired after a genetic test revealed her risk for a lung disorder...

...to a social worker, who despite outstanding performance reviews, was dismissed because of her family history of Huntington's disease.

Or consider the case of Heidi Williams, an individual diagnosed with alpha-1 antitrypsin deficiency. In 2004 she testified that a large health insurance company had denied coverage for her two children because they were carriers of alpha-1 antitrypsin disease.

GINA will make these discriminatory practices illegal by prohibiting health insurers from denying coverage, or charging person higher premiums, to a healthy individual because of a genetic predisposition to develop a disease in the future.

GINA also bars employers from using genetic information for hiring, firing, job placement or promotion decisions.

In the 12 years since I introduced the first version of this legislation, the need for it has grown exponentially. Scientific research has advanced so quickly that we cannot afford to wait any longer.

Genetic research offers immense potential for early treatment and prevention of numerous diseases.

Since the sequencing of the human genome was completed in 2003, researchers have identified genetic markers for a wide variety of chronic health conditions and new progress is being made every day.

Fifteen percent of all cancers, for example, have been found to have an inherited susceptibility, and ten percent of adult chronic diseases - like heart disease and diabetes, America's top killers - have a genetic component.

There are already over 15,500 recognized genetic disorders affecting 13 million Americans. Each and every one of us is estimated to be genetically predisposed to between 5 and 50 serious disorders.

And that is exactly why this bill is important to all of us, not just those with recognized disorders. There is not a single person on this planet that carries with them perfect genes - every one of us carries a predisposition to illnesses, and therefore we are all vulnerable to genetic discrimination.

To give you an idea of the potential that exists from this research, consider that genetic tests can tell a woman with a family history of breast cancer if she has the genetic mutation that can cause it, long before the cancer develops.

For these exciting scientific advances to continue, and for the potential of this technology to be realized, we need to make genetic testing something that is commonplace, rather than something that is feared.

But sadly, the threat of genetic discrimination - and the fear of being passed over for promotion, forced to pay more for health insurance, or even being denied coverage - is making men and women less likely to be tested and to take advantage of that potentially life-saving information.

Most importantly, if individuals do not participate in clinical trials, then we will never be able to reap the real benefits of genetic technology.

In a 2006 Cogent Research poll, 66% of respondents said they had concerns about how their genetic information would be stored and who would have access to it.

72% agreed that the government should establish laws and regulations to protect the privacy of individuals' genetic information. And 85% said that without amending current law, employers would use this information to discriminate.

Before I close, I want to reiterate the broad support that this bill enjoys. We have over 220 cosponsors behind this bill.

In past Congresses, the Senate has passed this bill twice with unanimous support. And I would like to thank the President who today issued a statement of administration policy in support of the bill.

I want to take a moment to thank the lead Republican cosponsor of this bill, Congresswoman Judy Biggert for her dedication to this bill, along with Congresswoman Anna Eshoo for being a strong advocate for this bill over the years.

I also want to thank Dr. Francis Collins for his support.

His testimonies over the years should have swayed even the firmest unbelievers that genetics has the potential to change our health care system as we know it.

Lastly, I want to thank the advocates from the health and science community. Over 200 organizations including HADASSAH support this bill.

GINA will do more than stamp out a new form of discrimination - it will help our country be a leader in a field of scientific research that holds as much promise as any other in history.

And it will allow us to realize the tremendous potential of genetic research without jeopardizing one of the most fundamental privacies that can be imagined.

M. Speaker, today is a momentous day.

And, I urge all my colleagues to support this bill

###