

## January 30, 2007 - Slaughter Testifies in Support of GINA

FOR IMMEDIATE RELEASE

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Slaughter Testifies in Support of GINA  
Genetic Non-Discrimination Legislation in Most Promising Position for Passage in 12 Years

Washington, DC - Rep. Louise M. Slaughter (D-NY-28), Chairwoman of the House Rules Committee, today advocated in support of the Genetic Information Non-discrimination Act (H.R. 493) before the Committee on Education and Labor's Subcommittee on Health, Employment, Labor, and Pensions.

"For the potential of genetic technology to be realized, we need to make genetic testing something that is commonplace, rather than something that is feared," Rep. Slaughter said. "But sadly, ongoing genetic discrimination is making men and women ever less likely to be tested and to participate in clinical trials."

"GINA will do more than stamp out a new form of discrimination, as important as that is. 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."

"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."

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

## BACKGROUND

H.R. 493, the Genetic Information Non-discrimination 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.

TEXT OF REP. SLAUGHTER'S REMARKS, AS PREPARED:

Testimony by the Honorable Louise M. Slaughter

Hearing on Protecting Workers from Genetic Discrimination

Committee on Education and Labor

Subcommittee on Health, Employment, Labor, and Pensions

January 30, 2007

Mr. Chairman, I want to thank you for having this important hearing today and for inviting me to testify. I hope that our discussion will help lead to the timely and decisive passage of the strong genetic non-discrimination legislation we have all been waiting for.

The Genetic Information Nondiscrimination Act, or GINA for short, is the culmination of a systematic, bipartisan effort to prohibit improper use of genetic information in workforce and insurance decisions.

GINA prohibits group health plans and health insurers from denying coverage to a healthy individual or charging that person higher premiums based solely on a genetic predisposition to develop a disease in the future. Furthermore, it bars employers from using an individual's genetic information when making hiring, firing, job placement or promotion decisions.

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

Since the sequencing of the human genome was completed in April of 2003, researchers have identified genetic markers for a variety of chronic health conditions, and increased the potential for early treatment and prevention of numerous diseases.

There are currently over 15,500 recognized genetic disorders affecting 13 million Americans, and every one of us is estimated to be genetically predisposed to between 5 and 50 serious disorders. Fifteen percent of all cancers, for example, have an inherited susceptibility, and ten percent of adult chronic diseases (like heart disease and diabetes, America's top killers) have a genetic component.

Fortunately, there are already genetic tests for over 1000 diseases, and hundreds more are under development. To give you an idea of the potential that exists, 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, ongoing genetic discrimination is making men and women ever less likely to be tested and to participate in clinical trials.

Significant examples of genetic discrimination already exist. Many already know about the Burlington Northern Santa Fe Corporation case, and the case involving Lawrence Livermore Laboratories.

But you may not know about the North Carolina woman who was fired after a genetic test had revealed her risk for a lung disorder, or the social worker whom, despite outstanding performance reviews, was dismissed because of her family history of Huntington's disease.

These abuses, along with others, have only fed growing public fear of genetic discrimination, leading many Americans to forgo genetic testing even if early detection of a particular genetic mutation may help avert premature death.

In a recent 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.

Even health care professionals are hesitant to make their genetic information available. 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.

Genetic discrimination is wrong on two fronts. First, it is critical to remember that simply carrying a given genetic mutation almost never guarantees that one will fall ill. A genetic flaw simply confers a level of risk upon the carrier.

Given that scientists cannot accurately predict when or whether a carrier will develop a genetic disorder, it seems both criminal and illogical to allow this information to be used by health insurers or employers for discriminatory purposes.

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

In a 2003 editorial, Dr. Francis Collins and James Watson made a persuasive argument in favor of non-discrimination legislation along these lines. They wrote, and I quote: "Genetic discrimination has the potential to affect people's lives in terms of jobs and insurance, but there is another dimension as well: It can slow the pace of the scientific discovery that will yield crucial medical advances. ... Without protections in place, individuals who do agree to participate [in studies] will represent a self-selected group that could skew research results, producing a negative impact on all of us who look to genetics to help find better ways of diagnosing, treating, and preventing disease." End quote.

As a scientist myself, I cannot overstate the importance of having a truly representative sample size in clinical trials to ascertain valid research results.

Let me close by reiterating the broad support that this bill enjoys.

It has substantial support from the health and science community. The Coalition for Genetic Fairness, which consists of over 140 organizations, has been outspoken in their support for GINA. I have here in my hand over 200 letters of support for GINA from a wide spectrum of health-related organizations.

And as of today, we have over 180 cosponsors, both Democrats and Republicans, standing behind this bill. The Senate has passed this bill twice with unanimous support, and even the White House has come out in support of genetic nondiscrimination legislation.

GINA will do more than stamp out a new form of discrimination, as important as that is. It will help our country to 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. Chairman, once again, let me thank you for the opportunity to speak at this hearing. I look forward to working with you and all the Members of this Subcommittee, as well as any other interested parties, to enact this bill.

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