

Statement of the Honorable Judy Biggert
Education and Labor Subcommittee on Health, Employment, Labor, and Pensions
Hearing on Protecting Workers from Genetic Discrimination
January 30, 2007

Thank you, Mr. Chairman, for holding this very important hearing today and for allowing me to participate. I also want to thank Subcommittee Members Mr. Rush, Mr. Boustany, Mr. Kildee, Mr. Hoekstra, Mr. Tierney, Mr. Marchant, and Mr. Hare, who are among the 175 cosponsors -- including 93 Republicans and 82 Democrats -- of this bipartisan bill. I hope today's testimony will encourage other members of this Subcommittee and our colleagues on the full Education and Labor Committee to support this vital legislation.

Mrs. Slaughter has eloquently addressed the public's fear of genetic discrimination and how it is a serious problem preventing Americans from utilizing genetic testing to improve their own health and reduce healthcare costs. I will focus my testimony on how this technology can save lives and money and why I think these savings will be important -- not just for businesses, but also for employees and their families. Finally, I want to address some of the concerns of the business community.

Genetic testing is the foundation of personalized and preventative medicine that focuses on:

- 1) Catching diseases earlier when they are cheaper and easier to treat;
- 2) Tailoring treatments to each of our individual genetic makeups;
and
- 3) Preventing the onset of disease in the first place.

Along every step of the way, these genetics-based approaches can save lives while having the added benefit of reducing healthcare costs.

For example, many women who test positive for the BRCA1 mutation have up to an 85% chance of getting breast cancer. Many choose to have a prophylactic mastectomy *before* the onset of disease, which significantly reduces the chance they will get breast cancer. At a cost

of roughly \$12,000, this option dramatically reduces breast cancer treatment costs that can run into hundreds of thousands of dollars.

Even for women who already have developed breast cancer, genetic testing can lead to serious cost savings. For example, the breast cancer drug Iressa costs \$25,000 a year, but there is a simple genetic test that will predict whether or not this drug will be successful, thereby sparing false hope and saving precious time and money.

I chose the example of breast cancer to help make the point that genetic testing can be deployed today to reduce healthcare costs. But we're not just talking about tests for breast cancer. We're talking about a thousand genetic tests that predict whether an individual is more likely to get a disease. And we're not talking about just helping a few people. Estimates show that on average, each of us carries dozens of genetic defects that put us at risk.

These widespread benefits have important implications to employers. Think about how vital this information could be to employer-provided wellness programs, which by their very nature focus on preventative medicine. Think about how much employers could save on healthcare while keeping their employees healthy and productive.

Now I know that this is at the heart of the debate within the employer community. It's the clash between those who see this legislation as a way to reduce healthcare costs versus those who see it as a new opportunity for frivolous and costly lawsuits. So I just want to take a moment to address the concerns of those employers by outlining what is required for an employer to be liable under this bill.

Genetic nondiscrimination isn't like race, age, or sex discrimination... it's not apparent. You can't tell someone's genetic makeup from just looking at him or her -- you have to dig, and you have to dig deep. In order for an employer to be liable under this act, he or she would have to *intentionally* and *deliberately* go looking for genetic information and then use it against an employee. An employer literally would have to go out of his way to discriminate and that would be a problem.

I understand the concerns of the skeptics in the business community. My record on business issues speaks for itself. I'm a supporter of business even by the business community's own standards. As the lead sponsor of this legislation during the 109th Congress, I met with them, discussed their concerns and worked with them.

I think that everyone involved worked in good faith on this issue and these groups can trust that I will continue to give their concerns fair and honest consideration. However, I do believe it is important to point out that the bill I introduced in the 109th Congress, which is the same as the bill we are considering today, is already a compromise bill that accommodates many of the concerns the business community expressed about the previous version of the legislation that was introduced in the 108th Congress, H.R. 1910.

Compared to H.R. 1910, the legislation that we consider today is different in four important ways. Our bill:

- 1) Has a clear and precise definition of genetic information;
- 2) Explicitly states that inadvertent acquisition of genetic information is not prohibited;
- 3) Requires that claimants first exhaust administrative state and federal procedures before seeking court damages or equitable relief; under H.R. 1910, claimants could have gone directly to court; and
- 4) Caps damages under existing Title VII standards, which include a small business threshold for coverage, and varying caps on damages depending on the size of the firm; H.R. 1910 had no damage caps.

As a result of these accommodations, this legislation is much more business friendly than H.R. 1910 from the 108th Congress. I would stress that I support these changes and they should be maintained.

Mr. Chairman, in passing this legislation, we have a unique opportunity to improve the health and lives of the American people. But we will never unlock the great promise of the Human Genome Project if Americans are too paranoid to undergo genetic testing. Without the protections offered by H.R. 493, these fears will persist,

research at NIH will slow, and Americans and American businesses will never realize the benefits and savings of gene-based medicines.

It's time the House joined the Senate and the President in supporting this critical bill.

Thank you and I look forward to your questions.