

Chairman Dingell at the Subcommittee on Health hearing entitled "H.R. 493, The Genetic Information Nondiscrimination Act"

Statement of Congressman John D. Dingell, Chairman
Committee on Energy and Commerce

SUBCOMMITTEE ON HEALTH
HEARING ENTITLED
"H.R. 493, THE GENETIC INFORMATION NONDISCRIMINATION ACT"
MARCH 8, 2007

Mr. Chairman, thank you for holding this hearing. We are here today to discuss H.R. 493, the "Genetic Information Nondiscrimination Act of 2007". Recent advances in the field of genetic research have made it possible to identify the genetic basis for human diseases. These incredible scientific breakthroughs have opened the door to early disease detection and treatment, as well as to individualized prevention strategies. While these advances hold promise for improving the health and well-being of all people, genetic information can also be used to discriminate against or stigmatize individuals with respect to health insurance and employment.

The short-term benefits of genetic testing lie largely in the information they provide about the risk of future disease and health. The value of genetic information is personal to individuals who may use this information to make decisions about reproduction, the types or amount of health, life, or disability insurance to purchase, or even career choices. As we will hear from Dr. Collins, science is only beginning to unlock the complex nature of genes and their contribution to the disease process. Experts in the field of genetics argue that a better understanding of genetics will lead to truly remarkable long-term benefits from genetic testing.

As this research continues to advance rapidly, genetic testing may be able to tell us about the probability of a health outcome without an accompanying treatment option. These advances give rise to the potential misuse of genetic information to discriminate in health insurance and employment. Concerns about privacy and misuse of genetic information need to be balanced with the potential of genetics and genetic technology to change how care is delivered and to personalize medical care and treatment of disease.

The Genetic Information Nondiscrimination Act (GINA) ensures that discoveries made possible by genetic research are used to improve health and not to discriminate against workers or their families.

In order to protect individuals from employment discrimination, this legislation would make it an unlawful employment practice for an employer, employment agency, labor organization, or training program to discriminate against an individual or deprive such an individual of employment opportunities because of genetic information. Furthermore, this legislation would treat genetic information as part of the individual's confidential medical record.

In order to protect individuals from insurance discrimination, H.R. 493 would prohibit insurers, in both the group and individual markets, from using genetic information to determine eligibility or establish differential premiums based on the genetic information of individuals or their family members.

This legislation is supported by the American Academy of Pediatrics, the American Cancer Society, the American Civil

Liberties Union, the Association of American Medical Colleges, the March of Dimes, the National Organization for Rare Disorders, the Susan G. Komen Breast Cancer Foundation, and dozens of other stakeholder organizations.

The Bush Administration favors enactment of genetic information nondiscrimination legislation. As recently as January 17th of this year, President Bush said, “I really want to make it clear to the Congress that I hope they pass legislation that makes genetic discrimination illegal. In other words, if a person is willing to share his or her genetic information, it is important that that information not be exploited in improper ways” and Congress can pass good legislation to prevent that from happening.”

I believe this is a good piece of legislation, one that has broad bipartisan support with 212 cosponsors from both sides of the aisle. I particularly commend Representatives Slaughter, Eshoo, Pallone, and Biggert for all of their hard work on this important bill. I look forward to the testimony of the witnesses here today.

Thank you.

Prepared by the Committee on Energy and Commerce
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