

July 1, 1999

THE GENETIC NONDISCRIMINATION IN HEALTH INSURANCE AND EMPLOYMENT ACT

HON. LOUISE McINTOSH SLAUGHTER

OF NEW YORK

IN THE HOUSE OF REPRESENTATIVES

Thursday, July 1, 1999

Ms. SLAUGHTER. Mr. Speaker, I am proud to rise today to announce the introduction of the Genetic Nondiscrimination in Health Insurance Employment Act, a bill that will protect all Americans against the misuse of their genetic information.

Genetic information is among the most powerful, personal, and private information we can have about ourselves. Increasingly, genetics can give us insights into the fundamental characteristics that make us individuals—into what makes our eyes blue, our skin freckled, our bones more prone to breaking, our family members unusually long-lived. Yet while genetic information can offer insights, it rarely extends guarantees. Few genes carry an absolute assurance of developing a given condition or disease. Rather, the vast majority of genes increase or decrease our health risks, interacting with a complex web of environmental and other factors to produce an actual health outcome.

Our understanding of genetics and the interplay between genes and outside influences is still in its infancy, but it is growing every day. The Human Genome Project, coordinated by the National Human Genome Research Institute, now predicts that we will have a "working draft" of the entire human genome by early in the year 2000. A complete, highly accurate transcript will be completed only perhaps two to three years later. In the meantime, science will continue racing ahead to identify genes associated with specific traits and diseases. Before long, new gene-based therapies will likely be available to treat genetic diseases, ushering in a new era in human medicine.

The promise of genetic research and technology seems almost limitless. Unfortunately, the potential for abuse of genetic information is also considerable. Many health insurers and employers have already expressed a keen interest in the potential to use genetic information. In some cases, this genetic information would not be used to pursue the best interests of the individuals involved. Health insurers may wish to use genetic data to determine which consumers are likely to be the most or least healthy, setting insurance premiums accordingly or denying coverage altogether. Employers could use genetic information in hiring or promotion decisions, or as a tool to keep their company's insurance premiums low. In either situation, such actions would effectively punish individuals for being born with certain genes.

Americans are deeply concerned about the possibility of genetic discrimination. In a recent poll of Better Homes & Gardens readers, fully 90 percent of respondents said they were extremely, very, or somewhat concerned when asked, "How concerned are you that [genetic] tests will be used to deny health insurance or even jobs?" Even more worrisome, evidence is emerging that many people are deciding not to participate in clinical trials or genetic re-

EXTENSIONS OF REMARKS

search because they fear their genetic information might not remain private. Clearly, we must protect the privacy of genetic information and prevent abuse of this data if we are to avoid damaging the prospects of genetic research for curing human ills.

The Genetic Nondiscrimination in Health Insurance and Employment Act would provide all Americans with the necessary guarantees that their genetic information will not be used against them. This bill would prevent insurers from raising insurance premiums or denying coverage based on predictive genetic information. It would also prohibit insurance companies from requiring disclosure of this sensitive information or revealing it to third parties without consent. These provisions are backed up with meaningful penalties and remedies.

In addition, this bill contains crucial provisions banning genetic discrimination in employment. Under this legislation, employers would be barred from failing to hire, firing, or discriminating against workers with respect to the compensation, terms or privileges of employment based on genetic information. Employers would be prohibited from collecting genetic information except in connection with a program to monitor biological effects of toxic substances in the workplace. Finally, the privacy of genetic information would be protected by preventing employers from disclosing this information to outside parties.

I am pleased to note that companion legislation is being introduced today by Senators TOM DASCHLE, EDWARD KENNEDY, TOM HARKIN, and CHRISTOPHER DODD. Our bill is supported by a broad range of organizations active on health care issues. I look forward to building a bipartisan coalition in support of this bill, which responds effectively to the concerns of the American people with regard to genetics.

Mr. Speaker, I urge the House leadership to schedule hearings immediately on the Genetic Nondiscrimination in Health Insurance and Employment Act. With completion of the human genome mapping imminent, we cannot afford to waste any more time in addressing these critical issues. Congress must act quickly to protect all Americans against genetic discrimination and secure the future of genetic research.

HEALTH OF THE AMERICAN PEOPLE

SPEECH OF

HON. NANCY PELOSI

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

Wednesday, June 30, 1999

Ms. PELOSI. Mr. Speaker, people from my district in San Francisco come to visit my office wanting to talk about their personal battle against disease. They include parents of children with juvenile diabetes, women fighting a breast cancer diagnosis, families of people with Parkinson's, and people struggling with HIV disease and AIDS.

They come to talk about different problems, but speak with one resounding voice about how they want Congress to respond. Their message to me, and to all of us, is that fund-

ing for the National Institutes of Health must be doubled over five years.

My colleagues, we must heed their message and continue to increase NIH funding to achieve this goal. As a member of the Appropriations Subcommittee on Labor-HHS-Education, I strongly supported last year's \$2 billion, or 15%, increase in the research budget at the NIH, bringing total funding to \$15.6 billion. And this year, I am an original cosponsor of H. Res. 89, legislation that expresses the sense of the House of Representatives that NIH funding should be increased by another \$2 billion in fiscal year 2000.

I support these increases because I believe we are on the verge of making great leaps ahead in our ability to treat and prevent a wide range of diseases. Dr. Harold Varmus, Director of NIH, has testified before the Labor-HHS-Education Subcommittee that, "discoveries are occurring at an unprecedented pace in biology and medicine, presaging revolutionary changes in medical practice during the next decade." We have a responsibility to take advantage of this enormous opportunity to advance science, fight disease, and save and prolong life.

There are many success stories to point to at NIH and many challenges that lie ahead, including eliminating health disparities, reinvigorating clinical research, finding cures and vaccines for hundreds of diseases including malaria, cancer and HIV, and mapping the human genome and making it accessible to scientists across the world.

As Dr. Varmus testified this year, "Throughout the world, the NIH is considered the leading force in mankind's continuing war against disease." Our wise investment in NIH is paying off. We must enter the new millennium investing in science that can unlock secrets of human disease and human health, and change our world for the better. I urge my colleagues to support a doubling in NIH funding over five years.

INTRODUCTION OF H.R. 2413, THE COMPUTER SECURITY ENHANCEMENT ACT OF 1999

HON. F. JAMES SENSENBRENNER, JR.

OF WISCONSIN

IN THE HOUSE OF REPRESENTATIVES

Thursday, July 1, 1999

Mr. SENSENBRENNER. Mr. Speaker, I am pleased to introduce, H.R. 2413, the Computer Security Enhancement Act of 1999, a bipartisan bill to address our government's computer security needs. Joining me as cosponsors of this important legislation is Mr. Bart Gordon of Tennessee and Mrs. Connie Morella of Maryland, the Chairwoman of the Science Committee's Technology Subcommittee.

The bill amends and updates the Computer Security Act of 1987 which gave the National Institute of Standards and Technology (NIST) the lead responsibility for developing security standards and technical guidelines for civilian government agencies' computer security. Specifically, the bill:

1. Reduces the cost and improves the availability of computer security technologies