

PRESIDENT CLINTON TAKES HISTORIC ACTION TO BAN GENETIC DISCRIMINATION IN THE FEDERAL WORKPLACE

February 8, 2000

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AMERICANS FEAR THAT THEIR GENETIC INFORMATION WILL BE MISUSED.

Progress in genetics has helped researchers and health care providers to detect and prevent health disorders; however, it can also be misused to discriminate against or stigmatize individuals. Some employers may try to use genetic tests to discriminate against workers -- even those who have not yet or who may never show signs of illness -- in order to avoid increased costs associated with workers who are genetically predisposed to particular ailments.

- **Genetic discrimination is real.** In a 1996 study published in *Science*, 15 percent of individuals at risk of developing a genetic condition said that they had been asked questions about genetic diseases on job applications. Thirteen percent of the respondents reported that they or another family member had been denied a job or fired from a job because of a genetic condition in the family.

- **Fear of discrimination is widespread.** Confidentiality of genetic test results is a major concern for the public. A 1997 study by the National Center for Genome Resources found that 63 percent of people would not take genetic tests if employers could access the results -- and that almost 50 percent of people believe that most employers will ask employees to take genetic tests in the future.

PREVENTING GENETIC DISCRIMINATION IN THE WORKPLACE. Today, the President will sign an executive order that prohibits every agency in the Federal government from using genetic testing in any hiring or promotion action. This executive order, endorsed by the American Medical Association, the American College of Medical Genetics, the National Society of Genetic Counselors, and the Genetic Alliance, will:

- **Prohibit federal employers from requiring or requesting genetic tests as a condition of being hired or receiving benefits.** Employers would not be able to request or require employees to undergo genetic tests in order to evaluate an employee's ability to perform his or her job.

Prohibit federal employers from using protected genetic information to classify employees in a manner that deprives them of advancement opportunities. Employers would not be able to deny employees promotions or overseas posts because of a genetic predisposition for certain illnesses.

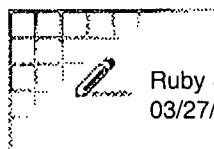
Provide strong privacy protections to any genetic information used for medical treatment and research. Under the EO, obtaining or disclosing genetic information about employees or potential employees is prohibited, except when it is necessary to provide medical treatment to employees, ensure workplace health and safety, or provide occupational and health researchers access to data. In every case where genetic information about employees is obtained, it will be subject to all Federal and state privacy protections.

PRESIDENT CALLS ON CONGRESS TO PROTECT THE PRIVATE GENETIC INFORMATION OF ALL AMERICANS. Today, President Clinton will endorse the Genetic Nondiscrimination in Health Insurance & Employment Act of 1999, introduced by Senator Daschle and Congresswoman Slaughter. This bill would extend the protections for genetic information included in the President's executive order to the private sector. In 1996, the President signed the Health Insurance Portability and Accountability Act (HIPAA), which prevents group health insurers from using genetic information to deny individuals health insurance benefits. The Daschle-Slaughter legislation finishes the job begun by HIPAA by ensuring that genetic information used to help predict, prevent, and treat diseases will not also be used to discriminate against Americans seeking employment, promotion, or health insurance.

AT THE PRESIDENT'S REQUEST, HHS ACCELERATES THEIR REVIEW OF PATIENT PROTECTIONS IN GENE THERAPY. Today, President Clinton will also address recent reports on lapses in gene therapy clinical trials. Specifically, that researchers failed to comply with federal regulations requiring the reporting of any serious illness or death, and patients may have been misinformed about the risks associated with the trials. At the President's request, the Secretary of Health and Human Services will instruct FDA and NIH to expedite their review of gene therapy guidelines and regulations -- to determine whether the current informed consent requirements need to be strengthened, and to ensure that information about these trials is shared with the public.

BUILDING ON THE CLINTON-GORE ADMINISTRATION'S STRONG COMMITMENT TO PROTECTING PRIVATE GENETIC INFORMATION. Since 1997, the President and Vice President have called for legislation that will guarantee that Americans who are self-employed or otherwise buy health insurance themselves will not lose or be denied that health insurance because of genetic information. Under the Clinton-Gore Administration, the Human Genome Research Project has made swift progress, and is on schedule to finish a draft of the human genome by April of 2000. While these advances promise great benefits, they also carry potential perils. Today's actions are part of the Administration's longstanding effort to ensure that we harness scientific advances to our most cherished values.

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Ruby Shamir
03/27/2000 10:26:45 AM

Record Type: Record

To: Heather H. Howard/OPD/EOP@EOP

cc:

Subject: Fact Sheet: President Clinton Takes Historic Action to Ban Genetic Discrimination in the Federal Workplace

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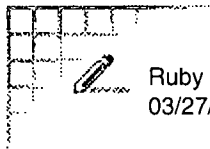
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