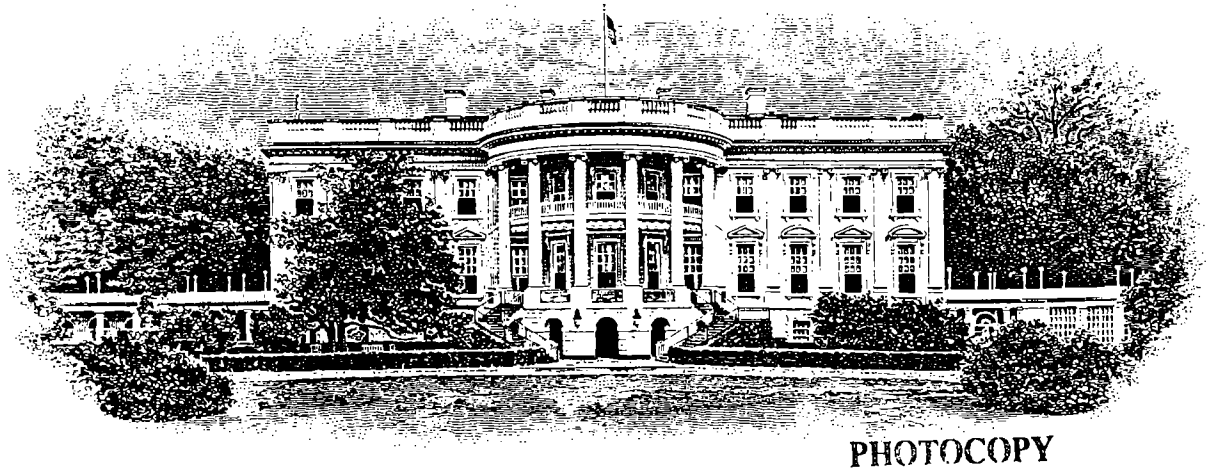
Robert's exception? example— GENETICS
get examples out

hazardous
Materials / working
conditions ~~that~~
make it necessary
to monitor
health of
workforce—
may involve
fam history.

The White House



John Roberts 457

CONTACT NAMES AND NUMBERS

Francis Collins, Director of the National Human Genome Research Institute 4461
Contact: Kathy Hudson 301 402 0955

Mary Davidson, Director of the Genetic Alliance
Contact: 202 966 5557

does this apply to people under contract

EXAMPLES

One individual was screened and learned he was a carrier of a single misspelled gene for Gaucher's disease. His carrier status indicates that he might pass this mutation to his children, but that he would never develop Gaucher's disease himself. He revealed this information when applying for a job and was denied the job because of his genetic status, even though it had no bearing on his present or future ability to perform a job. *(Violation of the EO's prohibition on collection of genetic information)*

Christine, who lives in Michigan, has a mother with Huntington's disease. She went to have the genetic test that would confirm her risk for developing the disease, and after receiving a positive test result, she was fired. *(Violation of EO's the discriminatory use of genetic information)*

A 53-year-old man at a job interview with an insurance company revealed that he had hemochromatosis but was asymptomatic. During the second interview, he was told that the company was interested in hiring him but would not be able to offer him health insurance because of his genetic condition. He agreed to this arrangement. During his third interview, the company representative told him that they would like to hire him, but were unable to do so because of his genetic condition. *(Violation of EO's the discriminatory use of genetic information)*

Richard, an engineer in the Southwest, received a tentative offer of employment. During the pre-employment medical exam, he was diagnosed with Klienfelters – a chromosomal disorder occurring in approximately one in 450 men. In the past, this diagnosis has been incorrectly associated with mental retardation and psychiatric problems. The employer withdrew their offer based on the results of this test. *(Violation of EO's the discriminatory use of genetic information)*

John was identified as being at high risk for hereditary hemochromatosis, a disease which is simple and inexpensive to treat but is deadly if left alone. John chose not to be tested because he was worried about being uninsurable and unemployable if these results became part of his medical record. *(Example of widespread fear of discrimination)*

A social worker named Kim lost her job after volunteering that her father had a fatal neurological condition, despite the fact that she was healthy, had never had a genetic test, and had no clinical diagnosis. *(Violation of EO's the discriminatory use of genetic information – illustrates the importance of the protections this EO places on family history)*

David, who lives in the Midwest, has a strong family history of colon cancer. He wants to do everything he can to increase his odds for a long and healthy life. Luckily, effective screening exists for colon cancer, using a procedure called colonoscopy. And yet, to get these medical services, David must disclose his family history in great detail...something he worries about. He is also contemplating genetic testing, which is available today for colon cancer risk. But he is worried about the results..who will get them.... and how they will be used. *(Example of widespread fear of discrimination)*

EXAMPLES OF GENETIC TESTS

Huntington's Disease
No Test Name

Colon Cancer
Test Names: PC and HPNCC

Diabetes
Test Name: MODY

Breast Cancer
Test Name: BRCA1 and BRCA2

EVENT: **GENETICS & PRIVACY EVENT**

DATE: TUESDAY, FEBRUARY 8, 2000

TIME: 12:00 PM-12:45 PM

LOCATION: AMERICAN ASSOCIATION FOR THE ADVANCEMENT OF SCIENCE
1200 New York Ave., NW, Washington, D.C. 20005

MEMBERS OF CONGRESS ATTENDING (3):

Rep. Greg Ganske (R-IA)

Rep. Louise Slaughter (D-NY)

Rep. Fred Upton (R-MI)

PRESIDENT CLINTON TAKES HISTORIC ACTION TO BAN GENETIC DISCRIMINATION IN THE FEDERAL WORKPLACE
February 8, 2000

Today, President Clinton will sign an executive order that prohibits every civilian Federal Department and agency from using genetic information in any hiring or promotion action. This historic action will prevent critical information from genetic tests used to help predict, prevent, and treat diseases being used against them by their employer. At an event at the American Association for the Advancement of Science, the President will endorse the Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, introduced by Senator Daschle and Congresswoman Slaughter, that will extend these employment protections to the private sector and finish the job begun with the Health Insurance Portability and Accountability Act to help extend protections to individuals purchasing health insurance. Finally, the President will also state his strong concerns about recent troubling reports about inappropriate use of gene therapies and will ask the Secretary of Health and Human Services to instruct FDA and NIH to expedite their review of gene therapy guidelines and regulations.

AMERICANS FEAR THAT THEIR GENETIC INFORMATION WILL BE MISUSED. Progress in the field of genetics has increased the ability of 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 seek to use genetic tests to discriminate against workers – even those who have not yet or who may never show signs of illness – because they want 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.** The 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, President Clinton 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 protected genetic information about employees or potential employees is prohibited, except when the collection or disclosure of genetic information by employers is necessary to provide medical treatment to employees, ensure workplace health and safety, and to provide researchers access to data. However, when genetic information about employees is obtained, it will be subject to 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 and ensures 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 that patients may have been misinformed about the risks associated with their participation in 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. The President today will make clear that 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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February 7, 2000

Genetic Discrimination Ban Sought

A.P. INDEXES: TOP STORIES | NEWS | SPORTS | BUSINESS | TECHNOLOGY | ENTERTAINMENT

Filed at 8:57 p.m. EST

By The Associated Press

WASHINGTON (AP) -- President Clinton plans to sign an executive order barring federal agencies from discriminating against workers on the basis of genetic tests, a step prompted by fears about rapid advances in scientific research.

The order, which congressional aides said Clinton would sign Tuesday, echoes a bill sponsored by Sens. Tom Daschle, D-S.D., and Edward M. Kennedy, D-Mass., barring employers from refusing to hire people at risk for health problems and insurers from refusing to sell them coverage.

Congressional officials, speaking on condition of anonymity, said Monday that Clinton would announce his decision during a speech at the American Association for the Advancement of Science. White House aides declined comment.

Advances in genetic testing will soon allow doctors to predict the medical futures of their patients. That has raised concerns that such information could be against those who are likely to suffer from cancer, diabetes, heart disease or other ailments.

Clinton has been speaking out on the issue for years. In his 1998 State of the Union speech, he declared that ``we must see that science serves humanity, not the other way around.''

``We must prevent the misuse of genetic tests to discriminate against any American,'' he said.

Ranit Schmelzer, Daschle's spokeswoman, said the Senate minority leader has long argued that ``as more information about people's future health becomes available it becomes important to protect that information.''

``People shouldn't be discriminated against in employment or in

other areas because of some genetic information that may be available on them," she said.

The order Clinton was signing would restrict federal agencies' abilities to collect or use genetic information, the sources said, including family medical histories. The order was limited to civilian employees of the federal government.

Exceptions to such data collection would be allowed in cases where workers give written consent as part of a health care program monitoring their medical conditions. Another exception would be granted for gathering information to study workplace safety.

In addition to the order, Clinton was expected to voice his support for the Daschle-Kennedy legislation, which would extend assurances against abuse of genetic information to the general public -- a step that would require congressional action.

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S. 1322/H.R. 2457
The Genetic Nondiscrimination in Health Insurance and Employment Act of 1999

* Indicates provisions also in S.326, the GOP bill; provisions without asterisk are unique to S.1322/H.R. 2457

TITLE I. PROHIBITION OF HEALTH INSURANCE DISCRIMINATION ON THE BASIS OF PREDICTIVE GENETIC INFORMATION

Applies to four areas of health insurance:

1. Self-insured or other health insurance plans governed by the Employee Retirement Income Security Act of 1974.*
2. Group health insurance plans governed by the Public Health Service Act.*
3. Individual insurance policies governed by the Public Health Service Act.*
4. Medigap insurance policies governed by the Social Security Act.

The protections outlined below are applied to all four areas.

3 things
(1.) prevent health ins. in group mkt

Discrimination

- Prohibits health plans or health insurance issuers from restricting enrollment based on predictive genetic information or information about genetic services.*
- Prohibits health plans or health insurance issuers from adjusting premium or contribution rates for individuals or groups based on predictive genetic information or information about genetic services.*

not in HIPAA

Genetic Testing

- Prohibits health plans or health insurance issuers from requesting or requiring an individual to undergo genetic testing. A health care professional treating a patient may suggest that a patient undergo a genetic test. NOT IN HIPAA

Collection of Predictive Genetic Information

- Prohibits health plans or health insurance issuers from requesting*, requiring*, collecting*, or purchasing predictive genetic information or information about genetic services. (Exception for payment of claims in strictly limited circumstances.)
  GOP bill allows requests for diagnosis, treatment, and payment. No limitation on

not in HIPAA

circumstance where request for payment purposes is allowed.

Disclosure of Predictive Genetic Information

- Prohibits disclosure of predictive genetic information or information about genetic services to:
  - Health plans or health insurance issuers (except for payment for health care under strictly limited circumstances). not in HIPAA
  - Employers.
  - The Medical Information Bureau, or other entities that collect or disseminate insurance information.
  - Other persons the Secretary of Labor or Health and Human Services may specify in regulations.

Enforcement

- Individual may bring private right of action in state or federal court. The court may award any appropriate legal or equitable relief.

- Secretary of Department of Health and Human Services or Secretary of Labor may bring an action in federal court for civil monetary penalties of up to $50,000 for first violation, up to $100,000 for subsequent violations.

Relationship to Other Laws

- This Act would not supersede any more protective state law on the confidentiality of genetic information or prohibiting discrimination on the basis of genetic information.

Definitions of Predictive Genetic Information and Genetic Test

- Predictive genetic information is defined as information about an individual's own genetic tests and information about genetic tests, diseases, or disorders of an individual's family members. Predictive genetic information does not include information about an individual's current health status, but predictive genetic information is protected regardless of health status.*
  GOP definition only protects genetic information in the absence of symptoms, clinical signs, or a diagnosis.

- Definition of genetic test includes analysis of DNA, RNA, chromosomes, proteins, and metabolites to detect genotypes, mutations, or chromosomal changes. The definition was developed from language created by the Task Force on Genetic Testing convened by the NIH-DOE Working Group on the Ethical, Legal, and Social Implications of Human Genome Research.*
  GOP definition only considers genetic tests in asymptomatic or undiagnosed individuals to be genetic tests. Test must be for the purpose of predicting risk; excludes genetic

information revealed inadvertently.

TITLE II. PROHIBITION OF EMPLOYMENT DISCRIMINATION ON THE BASIS OF PREDICTIVE GENETIC INFORMATION

Definitions:

- The definitions of genetic test and predictive genetic information are the same as those in Title I. Definition of employer and employee are from the Civil Rights Act.

- Genetic monitoring is defined as periodic examination to detect any damage to genetic material which might occur as a result of exposure to toxic substances in the workplace.

Discrimination (Applies to Employers, Employment Agencies, Labor Organizations, and Training Programs)

- Predictive genetic information or information about genetic services may not be used as a basis for:
  - Hiring, discharging, compensation, terms, or privileges of employment
  - Limiting, segregating, or classifying individuals
  - Representation by or referral for employment by an employment agency
  - Exclusion, expulsion from membership or other discrimination in a labor organization
  - Discrimination in admission to or employment by any training program

Collection of Predictive Genetic Information

- Predictive genetic information may not be requested or required by an employment agency, labor organization or training program.

- An employer may request genetic information only:
  - For monitoring of effects of toxic compound in the workplace, if employee has provided prior written authorization, the employee is informed of the results, the monitoring conforms to regulations that the Secretary of Labor may promulgate, and the employer only receives the results in aggregate.
  - If genetic services are directly provided by the employer with employee consent, and only the employee receives the results of the services.

Maintenance and Disclosure of Information

- Any predictive genetic information in the possession of an employer must be kept as a confidential part of the employee's medical record.

- Predictive genetic information may be disclosed only:
  - to the employee at his or her request

- to an occupational safety or public health researcher under 45CFR46 (the "Common Rule")
- under legal compulsion of a Federal court order
- to government officials for investigation of compliance with this Act.

Enforcement

- Individual may bring private right of action or class action in state or federal court. The court may award any appropriate legal or equitable relief. Action may be brought under the Equal Employment Opportunity Commission.

Relationship to Other Laws

- This Act is not intended to limit rights or protections under the Americans with Disabilities Act of 1990 or the Rehabilitation Act of 1973.

- This Act would not supersede any more protective state or federal law on the confidentiality of genetic information or prohibiting discrimination on the basis of genetic information.

- This Act does not apply to the Armed Forces Repository of Specimen Samples for the Identification of Remains

- The Act does not limit the statutory or regulatory authority of the Occupational Safety and Health Administration and the Mine Safety and Health Administration.

"Collins, Francis (NHGRI)" <francisc@exchange.nih.gov>
02/08/2000 08:17:58 AM

Record Type: Record

To: "Hudson, Kathy (NHGRI)" <hudsonk@exchange.nih.gov>, Devorah R. Adler/OPD/EOP

cc: "Fakunding, Patricia (NHGRI)" <FakundiP@exchange.nih.gov>
Subject: Collins Statement

Hi Kathy and Devorah,

Here is the current version of my statement. I might still do a little editing, but this should be very close. Please let me know right away if you see places that need changes.

It's a pleasure to work with you both on this! This is a great day for genetics and society.

Francis

It is a great pleasure to be here today to celebrate scientific advances in genetics that will improve our quality of life, and at the same time put in place social policies to prevent potential misuses of these new and powerful technologies.

Rapid advances in the Human Genome Project and the study of human genetics are providing powerful tools for us to understand the instructions in our genetic material. We are daily gaining insights into the mysteries of the human cell, how it works, and why sometimes...it doesn't. Though the Human Genome Project only got underway a decade ago, we are already seeing a great profusion of discoveries about the genetic basis of a very long list of diseases. Initially these discoveries related to relatively rare conditions, but increasingly now the same powerful approaches are uncovering hereditary factors in heart disease, diabetes, Parkinson's disease, asthma, and other common illnesses of our society. These revelations hold within them the promise of a true transformation of medical practice. Quite possibly before the end of the first decade of this new millennium, each of us may be able to learn our individual susceptibilities to common disorders, allowing the design of a program of effective individualized preventive medicine focused on lifestyle changes, diet and medical surveillance to keep us healthy. This will also enable us to spend our precious health care resources on wellness instead of relying on expensive and often imperfect treatments for advanced disease.

These same discoveries about genetics will lead us to predict who will respond most effectively to a particular drug therapy, and who may suffer a side effect and ought to avoid that particular drug. Furthermore, these remarkable advances will lead us to the next generation of designer drugs, focused in a much more precise way on the molecular basis of common illnesses, giving us a much more powerful set of targeted interventions to treat disease.

But genetic information and genetic technology can be used in ways that are

fundamentally unjust. Genetic information can be used as the basis for insidious discrimination. Already, with but a handful of genetic tests in common use, people have lost their jobs, lost their health insurance, and lost their economic wellbeing because of the misuse of genetic information. It is estimated that all of us carry dozens of glitches in our DNA -- so establishing principles of fair use of this information is important for all of us.

One individual was screened and learned he was a carrier of a single misspelled gene for Gaucher's disease. His carrier status indicates that he might pass this mutation to his children, but that he would never develop Gaucher's disease himself. He revealed this information when applying for a job and was denied the job because of his genetic status, even though it had no bearing on his present or future ability to perform a job.

David, who lives in the midwest, has a strong family history of colon cancer. He wants to do everything he can to increase his odds for a long and healthy life. Luckily, effective screening exists for colon cancer, using a procedure called colonoscopy. And yet, to get these medical services, David must disclose his family history in great detail...something he worries about. He is also contemplating genetic testing, which is available today for colon cancer risk. But he is worried about the results..who will get them.... and how they will be used. Will he lose his job? His health insurance?

Already in genetics research studies, we are seeing individuals who opt not to participate in research because of their fear that this information could fall into the wrong hands and be used to deny them a job or a promotion. As the clinical applications of genetics move out of the research lab and into clinical practice, this problem will only become more acute. As a nation, we have stated unequivocally in the Americans with Disabilities Act and the Rehabilitation Act that one's ability to do a job should be judged on just that... the ability to do the job.

The challenge, and it is a formidable one, is to nurture scientific exploration, encourage the translation of these new discoveries into life saving medicines, and to put in place public policies reflective of our core American values that prevent the unjust, unfair, and discriminatory use of genetic information.

Mr. President, you got it exactly right in your address in 1997 at Morgan State, where you said "We have not and we must not shrink from exploring the frontiers of science. But as we consider how to use the fruits of discovery, we must also never retreat from our commitment to human values, the good of society, our basic sense of right and wrong."

Mr. President, I know that you know that you and I, like any other two Americans, regardless of ethnic group, are 99.9% genetically identical. Even as we speak, scientists are creating a catalogue of the common genetic variants in the human family. This holds tremendous promise for understanding disease and, with intelligence and ingenuity, being able to develop new treatments to combat disease. To put in place today a policy to ensure these differences are not used as a basis for insidious discrimination is historic and visionary.

Mr. President, time and time again I have been amazed and gratified by your intense interest in science, the sophistication and intelligence you bring to complex issues in science and technology, and the vision you have for how

science and social values can be merged for the betterment of society. Today, genetics brings unprecedented opportunities for preventive medicine. I am pleased and proud that that with your forthought and wisdom, we can also practice preventive policy-making; to put in place the kind of protections that the public needs and deserves before we find ourselves in a needless crisis situation.

Antoine de Saint-Exupery, the author wrote, "Your goal is not to foresee the future, it is to enable it". The President's actions today, and the legislation which we hope will soon follow in the Congress, will enable the kind of future the American people deserve -- where medical advances are available for all, without fear of misuse.

And now, it is a high honor and a exceptional personal privilege to introduce to you the President of the United States of America, William Jefferson Clinton.

THE WHITE HOUSE

WASHINGTON

February 7, 2000

GENETIC DISCRIMINATION EVENT

DATE:	February 8, 2000
LOCATION:	American Association for the Advancement of Science, Washington, D.C.
BRIEFING TIME:	11:25am – 11:45am
EVENT TIME:	12:05pm – 12:50pm
FROM:	Bruce Reed, Chris Jennings

I. PURPOSE

To sign an executive order that prohibits every civilian Federal Department and agency from using genetic information in any hiring or promotion action.

II. BACKGROUND

Today, you will sign an executive order that prohibits every civilian Federal Department and agency from using genetic information in any hiring or promotion action. This historic action will prevent the critical information from genetic tests used to help predict, prevent, and treat diseases being used against them by their employer. At an event at the American Association for the Advancement of Science, you will endorse the Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, introduced by Senator Daschle and Congresswoman Slaughter, that will extend these employment protections to the private sector and finish the job begun with the Health Insurance Portability and Accountability Act to help extend protections to individuals purchasing health insurance. Finally, you will also state your strong concerns about recent troubling reports about inappropriate use of gene therapies and will ask the Secretary of Health and Human Services to instruct FDA and NIH to expedite their review of gene therapy guidelines and regulations.

AMERICANS FEAR THAT THEIR GENETIC INFORMATION WILL BE MISUSED. Progress in the field of genetics has increased the ability of researchers and health care providers to detect and prevent health disorders; however, it can also be misused to discriminate against or stigmatize individuals.

- **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.

- **Americans do not want employers to access private genetic information.** Some employers may seek to use genetic tests to discriminate against workers – even those who have not yet or who may never show signs of illness – because they fear increased costs associated with hiring workers likely to take sick leave, resign, or retire early for health reasons, file for workers' compensation, or use health care benefits excessively. A 1999 survey found that 95 percent of respondents believed that employers should not be able to obtain access to employees' genetic records or DNA without permission.

- **Fear of discrimination is widespread.** The 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, you 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 protected genetic information about employees or potential employees is prohibited, except when the collection or disclosure of genetic information by employers is necessary to provide medical treatment to employees, ensure workplace health and safety, and to provide researchers access to data. However, when genetic information about employees is obtained, it will be subject to Federal and state privacy protections.

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CALL ON CONGRESS TO ACT NOW TO PROTECT THE PRIVATE GENETIC INFORMATION OF ALL AMERICANS. Today, you will endorse the Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, introduced by Senator Daschle and Congresswoman Slaughter, that will extend the protections for genetic information included in the President's executive order to the private sector. This legislation finishes the job that HIPAA began and ensures that genetic information used to help predict, prevent, and treat diseases will not be used to discriminate against Americans seeking employment, being evaluated for a promotion, or purchasing health insurance.

REQUEST THAT HHS ACCELERATES THEIR REVIEW OF PATIENT PROTECTIONS IN GENE THERAPY CLINICAL TRIALS. Today, you will express your concern at the recent discovery that researchers failed to comply with Federal regulations requiring the reporting of any serious illness or death of patients in gene therapy clinical trials, and reports that patients may have been misinformed about the risks associated with their participation. You will ask the Secretary of Health and Human Services to instruct FDA and NIH to expedite their review of gene therapy guidelines and regulations to determine whether the current requirements to provide trial participants with informed consent need to be strengthened and develop new ways to ensure that information about these trials is shared with the public.

III. PARTICIPANTS

Briefing Participants:
Bruce Reed
Chris Jennings
Loretta Ucelli
Lowell Weiss

Greeters:
Richard Nicholson, Executive Officer, American Association for the Advancement of Science
Robert Zayas, Building Manager

Members of Cabinet In Attendance:
Secretary Donna Shalala
Director Janice LaChance, OPM
Ida Castro, Equal Employment Opportunity Commission