

gene therapies. Instead, we must do whatever it takes to address these legitimate concerns. We know if we do, the positive possibilities are absolutely endless.

I said this the other day, but I would like to reiterate—I think maybe I am so excited about this because of my age. I was in the generation of children who were the first treated with the polio vaccine. And for those of you who are much younger than me, you can't imagine what it was like for our parents to see the literal terror in our parents' eyes when we were children, paralyzed with fear that somehow we would be afflicted by what was then called infantile paralysis; and the sense of hope, the eagerness, the sort of nail-biting anticipation, when we learned of the Salk vaccine, and all of us were lined up to get our shots. Unless you were in our generation, you cannot imagine.

And the thought that every other problem that could affect the generation of my grandchildren could be visited with that level of relief and hope and exhilaration by the parents of our children's generation is something that is almost inexpressible.

We have to make the most of this. And we know, we have learned from over 200 years of experience as a nation, knocking down physical and intellectual frontiers, that we can only spread the benefits of new discoveries when we proceed in a manner that is consistent with our most ancient and cherished values. That is what this day is all about. So to all of you who have contributed to it, I thank you very, very much.

Now I would like to ask the Members of Congress who are here and members of the administration who are here, who have been involved in this to come up with me. And all I have to do is write my name. [*Laughter*] That's a pretty good deal. You can write the human genome code, and I'll write my name—[*laughter*]—and that takes full account of the one-tenth of one percent difference in our genetic makeup. [*Laughter*]

Thank you very much.

NOTE: The President spoke at 12:40 p.m. in the auditorium at the American Association for the Advancement of Science (AAAS). In his remarks, he referred to Shirley Malcolm, head of the directorate for education and human resources programs, and Richard S. Nicholson, member, board

of directors, and executive officer, AAAS; and Francis S. Collins, Director, National Human Genome Research Institute, National Institutes of Health.

Executive Order 13145—To Prohibit Discrimination in Federal Employment Based on Genetic Information

February 8, 2000

By the authority vested in me as President of the United States by the Constitution and the laws of the United States of America, it is ordered as follows:

Section 1. *Nondiscrimination in Federal Employment on the Basis of Protected Genetic Information.*

1–101. It is the policy of the Government of the United States to provide equal employment opportunity in Federal employment for all qualified persons and to prohibit discrimination against employees based on protected genetic information, or information about a request for or the receipt of genetic services. This policy of equal opportunity applies to every aspect of Federal employment.

1–102. The head of each Executive department and agency shall extend the policy set forth in section 1–101 to all its employees covered by section 717 of Title VII of the Civil Rights Act of 1964, as amended (42 U.S.C. 2000e–16).

1–103. Executive departments and agencies shall carry out the provisions of this order to the extent permitted by law and consistent with their statutory and regulatory authorities, and their enforcement mechanisms. The Equal Employment Opportunity Commission shall be responsible for coordinating the policy of the Government of the United States to prohibit discrimination against employees in Federal employment based on protected genetic information, or information about a request for or the receipt of genetic services.

Sec. 2. *Requirements Applicable to Employing Departments and Agencies.*

1–201. Definitions.

(a) The term “employee” shall include an employee, applicant for employment, or former employee covered by section 717 of

the Civil Rights Act of 1964, as amended (42 U.S.C. 2000e-16).

(b) Genetic monitoring means the periodic examination of employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of employment due to exposure to toxic substances in the workplace, in order to identify, evaluate, respond to the effects of, or control adverse environmental exposures in the workplace.

(c) Genetic services means health services, including genetic tests, provided to obtain, assess, or interpret genetic information for diagnostic or therapeutic purposes, or for genetic education or counseling.

(d) Genetic test means the analysis of human DNA, RNA, chromosomes, proteins, or certain metabolites in order to detect disease-related genotypes or mutations. Tests for metabolites fall within the definition of "genetic tests" when an excess or deficiency of the metabolites indicates the presence of a mutation or mutations. The conducting of metabolic tests by a department or agency that are not intended to reveal the presence of a mutation shall not be considered a violation of this order, regardless of the results of the tests. Test results revealing a mutation shall, however, be subject to the provisions of this order.

(e) Protected genetic information.

(1) In general, protected genetic information means:

- (A) information about an individual's genetic tests;
- (B) information about the genetic tests of an individual's family members; or
- (C) information about the occurrence of a disease, or medical condition or disorder in family members of the individual.

(2) Information about an individual's current health status (including information about sex, age, physical exams, and chemical, blood, or urine analyses) is not protected genetic information unless it is described in subparagraph (1).

1-202. In discharging their responsibilities under this order, departments and agencies

shall implement the following nondiscrimination requirements.

(a) The employing department or agency shall not discharge, fail or refuse to hire, or otherwise discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of that employee, because of protected genetic information with respect to the employee, or because of information about a request for or the receipt of genetic services by such employee.

(b) The employing department or agency shall not limit, segregate, or classify employees in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect that employee's status, because of protected genetic information with respect to the employee or because of information about a request for or the receipt of genetic services by such employee.

(c) The employing department or agency shall not request, require, collect, or purchase protected genetic information with respect to an employee, or information about a request for or the receipt of genetic services by such employee.

(d) The employing department or agency shall not disclose protected genetic information with respect to an employee, or information about a request for or the receipt of genetic services by an employee except:

- (1) to the employee who is the subject of the information, at his or her request;
- (2) to an occupational or other health researcher, if the research conducted complies with the regulations and protections provided for under part 46 of title 45, of the Code of Federal Regulations;
- (3) if required by a Federal statute, congressional subpoena, or an order issued by a court of competent jurisdiction, except that if the subpoena or court order was secured without the knowledge of the individual to whom the information refers, the employer shall provide the individual with adequate notice to challenge the subpoena or court order, unless the

subpoena or court order also imposes confidentiality requirements; or

- (4) to executive branch officials investigating compliance with this order, if the information is relevant to the investigation.

(e) The employing department or agency shall not maintain protected genetic information or information about a request for or the receipt of genetic services in general personnel files; such information shall be treated as confidential medical records and kept separate from personnel files.

Sec. 3. Exceptions.

1-301. The following exceptions shall apply to the nondiscrimination requirements set forth in section 1-202.

(a) The employing department or agency may request or require information defined in section 1-201(e)(1)(C) with respect to an applicant who has been given a conditional offer of employment or to an employee if:

- (1) the request or requirement is consistent with the Rehabilitation Act and other applicable law;
- (2) the information obtained is to be used exclusively to assess whether further medical evaluation is needed to diagnose a current disease, or medical condition or disorder, or under the terms of section 1-301(b) of this order;
- (3) such current disease, or medical condition or disorder could prevent the applicant or employee from performing the essential functions of the position held or desired; and
- (4) the information defined in section 1-201(e)(1)(C) of this order will not be disclosed to persons other than medical personnel involved in or responsible for assessing whether further medical evaluation is needed to diagnose a current disease, or medical condition or disorder, or under the terms of section 1-301(b) of this order.

(b) The employing department or agency may request, collect, or purchase protected genetic information with respect to an employee, or any information about a request for or receipt of genetic services by such employee if:

- (1) the employee uses genetic or health care services provided by the employer (other than use pursuant to section 1-301(a) of this order);

- (2) the employee who uses the genetic or health care services has provided prior knowing, voluntary, and written authorization to the employer to collect protected genetic information;

- (3) the person who performs the genetic or health care services does not disclose protected genetic information to anyone except to the employee who uses the services for treatment of the individual; pursuant to section 1-202(d) of this order; for program evaluation or assessment; for compiling and analyzing information in anticipation of or for use in a civil or criminal legal proceeding; or for payment or accounting purposes, to verify that the service was performed (but in such cases the genetic information itself cannot be disclosed);

- (4) such information is not used in violation of sections 1-202(a) or 1-202(b) of this order.

(c) The employing department or agency may collect protected genetic information with respect to an employee if the requirements of part 46 of title 45 of the Code of Federal Regulations are met.

(d) Genetic monitoring of biological effects of toxic substances in the workplace shall be permitted if all of the following conditions are met:

- (1) the employee has provided prior, knowing, voluntary, and written authorization;

- (2) the employee is notified when the results of the monitoring are available and, at that time, the employer makes any protected genetic information that may have been acquired during the monitoring available to the employee and informs the employee how to obtain such information;

- (3) the monitoring conforms to any genetic monitoring regulations that may

be promulgated by the Secretary of Labor; and

- (4) the employer, excluding any licensed health care professionals that are involved in the genetic monitoring program, receives results of the monitoring only in aggregate terms that do not disclose the identity of specific employees.

(e) This order does not limit the statutory authority of a Federal department or agency to:

- (1) promulgate or enforce workplace safety and health laws and regulations;
- (2) conduct or sponsor occupational or other health research that is conducted in compliance with regulations at part 46 of title 45, of the Code of Federal Regulations; or
- (3) collect protected genetic information as a part of a lawful program, the primary purpose of which is to carry out identification purposes.

Sec. 4. Miscellaneous.

1-401. The head of each department and agency shall take appropriate action to disseminate this policy and, to this end, shall designate a high level official responsible for carrying out its responsibilities under this order.

1-402. Nothing in this order shall be construed to:

(a) limit the rights or protections of an individual under the Rehabilitation Act of 1973 (29 U.S.C. 701, *et seq.*), the Privacy Act of 1974 (5 U.S.C. 552a), or other applicable law; or

(b) require specific benefits for an employee or dependent under the Federal Employees Health Benefits Program or similar program.

1-403. This order clarifies and makes uniform Administration policy and does not create any right or benefit, substantive or procedural, enforceable at law by a party against the United States, its officers or employees, or any other person.

William J. Clinton

The White House,
February 8, 2000.

[Filed with the Office of the Federal Register, 8:45 a.m., February 9, 2000]

NOTE: This Executive order was published in the *Federal Register* on February 10.

**Remarks on Presenting the
Congressional Medal of Honor
to Alfred Rascon**

February 8, 2000

The President. Colonel, thank you for that prayer. General Hicks, Secretary Cohen, Secretary West, Secretary Richardson, Secretary Caldera, General Shelton, General Ralston, members of the Joint Chiefs, all the Members of Congress who are here—and we have quite a distinguished array of them. We thank them all for coming. I'd like to ask the Members of Congress who are here to stand so you'll see how many we have. We're very grateful to you for your presence here. Thank you.

When the Medal of Honor was conceived in 1861, some Americans actually worried that it might be a bad thing, that the medals would be seen as somehow too aristocratic, and that there was no need for them in a genuinely democratic society. Today, we award the Medal of Honor, secure in the knowledge that people like Alfred Rascon have kept our democracy alive all these years.

We bestow the medal knowing that America would not have survived were it not for people like him, who, generation after generation, have always renewed the extraordinary gift of freedom for their fellow citizens.

Under any circumstances, a Medal of Honor ceremony is an event of great importance. Today it is especially so: for the rare quality of heroism on display that long-ago day in 1966; for the long, patient wait for recognition; for Alfred's decision to devote his life both before and after 1966 to a nation he was not born in.

Alfred Rascon was born in Mexico on September 10, 1945, just 8 days after the formal surrender ending World War II. When he was very young, his parents came to America for a better chance. They ended up in Oxnard, north of Los Angeles. And when Alfred started grade school, he still spoke not