Genetic Discrimination and the Americans with Disabilities Act
Statement of the Joint Working Group
on Ethical, Legal, and Social Issues of
Human Genome Research
Human Genome Program, Department of Energy
National Center for Human Genome Research, National Institutes of Health
Meeting at Los Alamos National Laboratory
29 April, 1991

The Joint Working Group on Ethical, Legal, and Social Issues in Human Genome Research met at Los Alamos National Laboratory on 29 April 1991. This working group is sponsored by the Human Genome Program, US Department of Energy and the National Center for Human Genome Research, National Institutes of Health. The Joint Working Group brought together experts from law, human genetics, voluntary health organizations, and other fields to discuss the Americans with Disabilities Act. The Focus of discussion was how and to what degree the Americans with Disabilities Act will prevent discrimination against those bearing particular genes that confer susceptibility to disease or disability. The Working Group prepared the following recommendations that it will forward to its parent committee, the NIH-DOE Joint Subcommittee on Human Genome Research, for consideration.

The effort to map the human genome will, over the coming decade, create the tools to analyze human genetics in enormously greater detail than hitherto possible. The joint NIH-DOE five-year goals for human genome research, for example, call for a set of index markers that span all the human chromosomes in the next several years, and a high resolution map of the entire genome within five years. Such a map will greatly enhance our ability to identify genetic factors that influence disease and disability. New technologies will introduce new choices for individuals, and also difficult public policy choices. The rapidly expanding power of human molecular genetics promises great benefits, but also raises the specter of genetic discrimination -- that is, the use of genetic information to classify persons into groups, some of which are denied opportunities offered to other groups.

Access to jobs is a central concern. The Americans with Disabilities Act is intended to address potential issues of great concern to those who might be subject to discrimination on the basis of genes they bear. These comments do not reflect on past actions or policies of the sponsoring agencies or other groups. They are recommendations intended to bring this issue to the attention of the Equal Employment Opportunity Commission.

I. Coverage of Genetic Conditions

Although individuals who already manifest symptoms of a severe genetic disease and individuals at increased risk of a severe genetic disease are covered by Section 3(2) and Section 1630.2, the proposed regulations do not expressly state that unaffected heterozygote carriers of recessive disorders and x-linked disorders are covered when the basis for their exclusion is the fear that the individual is at risk of parenting a child who will have the condition. Congress sough to prohibit discrimination based on associations in enacting Section 102(b)(4). Because of the substantial economic incentives for employers to

engage in this form of discrimination, EEOC should revise its proposed Section 1630.21 to provide that "is regarded as having such an impairment" includes action based on an individual's genotype.

II. Job-Related Employment Entrance Examinations

Proposed Section 1630.14(b)(3) provides that an employment entrance examination administered after a conditional offer of employment need not be job-related, although only job-related criteria may be used as the basis for screening out otherwise qualified individuals. In effect, employers are permitted to require, as a condition of employment, that individuals accede to medical examination, including genetic tests, whose results may not be used for screening purposes.

While purporting to prohibit discrimination, the regulation facilitates discrimination because neither the ADA nor the EEOC regulations have yet altered the existing common law of employment relations which provides that: conditional offerees have no right to know what medical tests are being performed (e.g. the specific tests being run on a blood sample); conditional offerees have no right to know the results of genetic and other medical tests; and conditional offerees have not right to know why a conditional offer of employment was withdrawn. Because this information is only discoverable, if at all, after the filing of a discrimination claim, it facilitates surreptitious testing and discriminatory reliance upon non-job-related criteria in making decisions.

Equally important, the ADA seeks to promote autonomy and confidentiality. Even genetic and other medical examinations of employees of some efficacy in promoting employee health generally. such as mandatory, comprehensive annual physicals, are not permitted unless they are job-related or voluntary. Section 102(c)(4). When medical disclosures are made, they must be confidential. Section 102(c)(3).

Under this proposed regulation, employers would be permitted to perform genetic testing, HIV testing, and other non-job-related medical examinations of conditional offerees. This could not have been intended by Congress.

EEOC should amend Section 1630.12(b)(3) to provide that post-offer, employment entrance medical examinations must be limited to assessing job-related physical and mental conditions.

III. Access to Genetic Information in Medical Records and Health Insurance Claims

A. Medical Records

Employers conducting lawful, job-related medical assessments may need to obtain information about the individual's medical condition. Current practice is for employers to require that the individual sign a release authorizing the health care provider to release the records. Hospital records and medical records of an individual's treating physician often contain much information of a highly confidential, non-job related nature, including genetic information. It is infeasible for the health care provider to "sanitize" the records before disclosure.

EEOC should prohibit employers from requesting or requiring that applicants and employees authorize a release of medical records that are likely to contain medical information of a non-job related nature. An employer may only require that the individual authorize his or her health care provider to respond to specific, job-related questions.

B. Health Insurance Claims

A significant, but largely unrecognized threat to the confidentiality of employee genetic and medical information exists in the method of paying employee health insurance claims. Perhaps most pronounced at large, self-insured companies, these breaches of confidentiality are very common. When a health care provider submits a bill for payment it will customarily contain an explanation of the nature of the services rendered, either by description or code number. These bills are processed by the benefits office, not the medial department, and access to the information may be widespread.

EEOC should initiate rulemaking proceedings to determine the most effective way of protecting the privacy of health insurance claims information. One possible option is for each employee to have a separate medical claims number and have claims submitted by number only.

Nancy S. Wexler, Ph.D.
Chair, Joint Working Group on Ethical, Legal and Social Issues in Human Genome Research and
President, Hereditary Disease Foundation

Jonathan Beckwith, Ph.D.
Harvard Medical School

Robert M. Cook-Deegan, M.D.
Institute of Medicine, National Academy of Sciences

Patricia King, J.D.
Georgetown University Law Center

Robert E. Murray, Jr., M.D.
Howard University College of Medicine

Thomas H. Murray, Ph.D.
Case Western Reserve University