

Employment Issue Update:

EMPLOYMENT DISCRIMINATION

The public is concerned that the increased ease of access to genetic information by employers will result in discrimination. This concern is affecting the choices individuals make about their own health care and their decisions whether to participate in research. Survey results released in March, 1998 by the National Center for Genome Resources found that 85 percent of those surveyed believed that employers should be prohibited from obtaining information about an individual's genetic conditions, risks and predispositions. ⁽¹⁾ In the same survey, a majority of respondents (63 percent) said they probably or definitely would not take a genetic test if employers or insurers would have access to the results.

Recommendations for Action

On October, 4, 1996, the NIH-DOE Ethical, Legal and Social Implications (ELSI) Working Group and the National Action Plan on Breast Cancer (NAPBC) cosponsored a workshop on genetic discrimination and the workplace to offer guidance for state and federal policy makers to protect against genetic discrimination and to promote privacy in the workplace. ⁽²⁾ In March, 1997, the findings and recommendations of the workshop were published in *Science*. ⁽³⁾

Subsequently, in July, 1997, the White House asked the Department of Labor to develop a report on genetic information and the workplace. NHGRI, along with other representatives of the Department of Health and Human Services, the Equal Employment Opportunity Commission and the Department of Justice were invited to work with the Department of Labor in developing this report and a set of policy principles.

On January 20, 1998, Vice President Al Gore announced that the Clinton Administration was calling for legislation to bar employers from discriminating against workers in hiring or promotion because of their genetic makeup and released a Department of Labor report summarizing the Administration's recommendations. ⁽⁴⁾

The report and principles are based on the NIH-DOE ELSI Working Group and NAPBC recommendations and would:

- Prohibit employers from requiring or requesting a genetic test or genetic information as a condition of being hired or receiving benefits.
- Prohibit employers from using genetic information to limit, segregate, or classify employees in a way that would deprive them of employment opportunities.
- Prohibit employers from obtaining or disclosing genetic information about employees or potential employees under most circumstances.
- Permit the collection, and/or disclosure of genetic information and genetic testing by employers only in limited situations necessary to ensure workplace health and safety, and to provide occupational and health researchers access to data.

On February 8, 2000, President Clinton signed an executive order that prohibits federal departments and agencies from using genetic information in any hiring or promotion action. In addition, the President called on Congress to protect the private genetic information of all

Americans and endorsed the Genetic Nondiscrimination in Health Insurance & Employment Act of 1999 (S. 1322/H.R. 2457), 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 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.

Current Status - Federal

Federal legislation implementing the recommendations of the NAPBC and the NIH-DOE Working Group was introduced in the House and Senate during the last session of Congress [S. 1045, *Genetic Justice Act*, (Senator Tom Daschle)]; H.R. 2275, *Genetic Employment Protection Act of 1997*, [Rep. Nita Lowey (D-NY)/Rep. Rick Lazio (R-NY)]. This legislation did not pass. Similar legislation has been introduced in the 106th Congress:

- S. 1322 *Genetic Nondiscrimination in Health Insurance and Employment Act of 1999*
(Senator Tom Daschle);
- H.R. 2457 *Genetic Nondiscrimination in Health Insurance and Employment Act of 1999*
(Representative Louise Slaughter);
- H.R. 2555 *Genetic Privacy and Nondiscrimination Act of 1999*
(Representative Cliff Stearns)

Current Status - States

Twenty-three states have enacted legislation regarding genetic information and the workplace. In the 1999 state legislative sessions, there were over 100 bills introduced regarding genetic discrimination in the workplace and/or genetic discrimination by insurers. Some of these state bills would have inaugurated genetic antidiscrimination protection, while other bills would have modified or clarified existing antidiscrimination legislation. In 1999, Kansas and Nevada enacted legislation to prohibit genetic discrimination by employers. To date in 2000, numerous genetic antidiscrimination bills have been introduced in state legislatures.

ENDNOTES

1. National Center for Genome Resources survey, "Attitudes Toward Genetic Testing", March 4, 1998.
2. "Genetic Information and the Workplace: A Case Study on Breast Cancer," Bethesda, MD, October 4, 1996, workshop sponsored by the National Action Plan on Breast Cancer (NAPBC) and the NIH-DOE Working Group on the Ethical, Legal, and Social Implications of Human Genome Research.
3. Rothenberg, Karen, et al, "Genetic Information and the Workplace: Legislative Approaches and Policy Challenges," *Science*, Volume 275, 1755-1757, 21 March 1997.
4. "Genetic Information and the Workplace," Department of Labor, Department of Health and Human Services, Equal Employment Opportunity Commission, Department of Justice; January 20, 1998 (www.nhgri.nih.gov:80/NEWS/genetic_discrim/).

http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/99upemp.htm