

**Note: Comment Period  
Extended to October 12**

**The Secretary's Advisory Committee on Genetics, Health, and Society  
Hearing on Genetic Discrimination  
October 18, 2004**

The issue of genetic discrimination is a high priority for the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS). In an effort to raise awareness about the problem, the Committee is seeking public comments from individuals who:

- Have experienced genetic discrimination in health insurance or in employment.
- Fear the potential impact of genetic discrimination on either health insurance or employment.
- Have paid out-of-pocket for services to exclude genetic information from medical records.
- Are health care providers and have had patients experience genetic discrimination; express concern about genetic discrimination; or taken steps to avoid genetic discrimination (for example, not undergoing genetic testing or keeping the results out of a medical record).

SACGHS will be holding a hearing on October 18, 2004 to gather information from members of the public about the scope and nature of genetic discrimination. The Committee is particularly interested in learning about cases of genetic discrimination that are based on predictive genetic information, pre-symptomatic genetic disease, or carrier status.

President Bush has called for Federal legislation to prohibit genetic discrimination in health insurance and employment. In October 2003, the Senate unanimously passed the Genetic Information Nondiscrimination Act, and advocates are pressing for action in the House of Representatives. In July 2004, the House Subcommittee on Employer-Employee Relations of the Committee on Education and the Workforce held a hearing on the issue of genetic discrimination. In spite of broad bipartisan support for the legislation, there is opposition and it appears to be preventing further progress in the House. The fear of genetic discrimination and its adverse consequences is well-documented and regarded by many as sufficient justification for Federal legislation. However, opponents argue that there is insufficient evidence that genetic discrimination is occurring and thus legislation is not warranted at this time. SACGHS hopes that the information gathered during the hearing will help address the concerns of the bill's opponents.

SACGHS was established to serve as a forum for deliberation on the ethical, legal and social issues at the intersection of genetics, health and society and to advise the Secretary of Health and Human Services about these issues. For more information about the Committee and its meetings, as well as copies of the Committee's correspondence with the Secretary on this issue, please visit <http://www4.od.nih.gov/oba/SACGHS.HTM>.

Please send your written comments to SACGHS by **October 12, 2004** in care of Amanda Sarata at [sarataa@od.nih.gov](mailto:sarataa@od.nih.gov) or by fax to 301-496-9839.