



Secretary's Advisory Committee on Genetic Testing  
National Institutes of Health  
6705 Rockledge Drive, Suite 750  
Bethesda, Maryland 20892  
<http://www4.od.nih.gov/oba/sacgt.htm>

May 3, 2001

The Honorable Tommy G. Thompson  
Secretary of Health and Human Services  
The U.S. Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

Dear Secretary Thompson:

On behalf of the Secretary's Advisory Committee on Genetic Testing (SACGT), I am writing to express our support for Federal legislation prohibiting discrimination on the basis of genetic information. While we recognize the importance of the use of genetic information in the provision of health care services, we urge the Administration to support much needed Federal legislation to prevent genetic discrimination in health insurance and employment, and to eliminate the fear of discrimination that currently prevents many individuals from taking advantage of genetic tests.

During consultations with the public SACGT heard from many Americans who are concerned about the misuse of personal genetic information by third parties, such as health insurers and employers, and the potential for discrimination based on that information. Many stated that the fear of genetic discrimination would dissuade them from undergoing a genetic test or participating in genetic research studies. Others stated that they would pay out-of-pocket for a genetic test to prevent the results from being placed in their medical record. Such concerns are a deterrent to advances in the field of genetic testing and may limit the realization of the benefits of genetic testing.


Comprehensive Federal legislation should apply to individual and group health insurance providers as well as employers, employment agencies, labor organizations, and labor-management committees. It should include the following key points:

- Like other medical information, genetic information should be afforded a high level of privacy and confidentiality protection.

- The definition of genetic information should encompass information about genes, gene products, or inherited characteristics obtained from a genetic test of an individual or family member, including information about the request for or receipt of genetic services by an individual or family member, and information about the occurrence of a disease or disorder in family members.
- Health insurance providers should be prohibited from requesting or requiring an individual to undergo a genetic test.
- Health insurance providers should be prohibited from using genetic information to deny or limit any health care coverage or establish eligibility, continuation, enrollment or contribution requirements.
- Health insurance providers should be prohibited from establishing differential rates or premium payments based solely on genetic information.
- The failure or refusal to hire or the discharge of any individual, or discrimination against any individual in employment-related matters (e.g. benefits, compensation), because of genetic information should not be permitted.
- Genetic information should not be requested, required, collected or purchased by employers or their agents unless: it is for the purpose of genetic monitoring of biologic effects of toxic substances in the workplace; the employee has provided prior, knowing, voluntary, and written authorization; individual monitoring results are made available to the employee; and the results of the monitoring are received by employers or their agents only in aggregate terms that do not disclose the identity of specific employees.
- Federal provisions relating to genetic information should not supercede more stringent State provisions.

We believe that enactment of legislation based on these key points will prevent misuse of genetic information in employment and health insurance, and will minimize the fear of genetic discrimination. We strongly urge the Administration to make the passage of Federal legislation to prohibit genetic discrimination a high priority issue.

Sincerely,

  
Edward R.B. McCabe, M.D., Ph.D.  
Chair