



Secretary's Advisory Committee on Genetic Testing
National Institutes of Health
6000 Executive Boulevard, Suite 302
Bethesda, Maryland 20892
<http://www4.od.nih.gov/oba/sacgt.htm>

April 24, 2000

The Honorable Donna E. Shalala
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 Shalala:

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. Effective Federal legislation is needed to eliminate the fear of discrimination that currently prevents many individuals from taking advantage of advances in genetic research; to eliminate discrimination that prevents qualified workers from getting or keeping jobs; and, to eliminate health insurance discrimination based on predictive genetic information.

In June 1999, Assistant Secretary for Health and Surgeon General Dr. David Satcher asked SACGT to assess, in consultation with the public, the adequacy of current oversight of genetic tests and, if warranted, recommend options for additional oversight. Our report on this important topic will be finalized and transmitted to you and Dr. Satcher in the near future. At SACGT's February 24-25, 2000 meeting, we reviewed public comments received during a 60-day comment period on the oversight of genetic tests. Many commenters expressed concern about the use of personal genetic information by third parties such as health insurers 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 to prevent genetic test results from being placed in their medical record.

At our February meeting, we were also briefed by the Honorable Paul Miller, Commissioner, Equal Employment Opportunity Commission, on the implementation of the President's Executive Order to prohibit discrimination in Federal employment based on genetic information. We applaud the President's action on this important issue. We were also briefed by Congressional staff on the prospects for passage of genetic discrimination legislation.

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SACGT recognizes the tremendous potential benefits of genetic testing, but also acknowledges that genetic testing can result in harm if information derived from genetic tests is used inappropriately. The public's concern reinforces SACGT's belief that fear of genetic discrimination is a deterrent to advances in the field of genetic testing and that this fear may limit the realization of the benefits of genetic testing.

SACGT supports Federal legislation to prohibit genetic discrimination in the workplace and to prohibit all health plans from denying coverage or raising premiums on the basis of predictive genetic information. We commend the Administration's efforts to press for Federal protections in this area and urge you to make the passage of Federal legislation to prohibit genetic discrimination a high priority issue.

Sincerely,

A handwritten signature in cursive script, appearing to read "Ed McCabe".

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