



THE SECRETARY OF HEALTH AND HUMAN SERVICES  
WASHINGTON, D.C. 20201

**JUL 26 2000**

Edward R.B. McCabe, M.D., Ph.D.  
Chairman  
Secretary's Advisory Committee on Genetic Testing 6000 Executive Boulevard, Suite 302  
Bethesda, Maryland 20892

Dear Dr. McCabe

Thank you for your letter of April 24, 2000, requesting that I make the enactment of legislation prohibiting genetic discrimination a high priority. The Administration believes that Americans should be protected from third-party use of genetic information to discriminate. For the past several years, we have been working with Congress to enact such protections.

On February 8, 2000, the President signed Executive Order 13145 which prohibits the Federal government from discriminating on the basis of protected genetic information in hiring and promotion decisions. Through this action, the President hopes to set an example for private- sector employers and to encourage Congress to pass legislation. At the time the President signed the Executive Order, he also announced his support for H.R. 2457/S.1322, the Genetic Nondiscrimination in Health Insurance and Employment Act, introduced by Representative Louise Slaughter (D-NY) and Senator Tom Daschle (D-SD). In addition, in his January 27, 2000, State of the Union address, the President called for congressional action to prohibit genetic discrimination by employers and health insurers. At the historic announcement at the White House on June 26 about the completion of the working draft assemblies of the human genome, the President again underscored the need for action to guarantee that genetic information cannot be used to stigmatize or discriminate against any individual or group.

There are several pieces of legislation pending in Congress that would protect against genetic discrimination, an important one being the Slaughter-Daschle bill. This legislation would improve upon existing protections in P.L. 104-191, the Health Insurance Portability and Accountability Act (HIP AA) of 1996. HIP AA prohibits group health plans from using genetic information either to deny an individual health insurance benefits or to raise his or her premiums separately from the group. The Slaughter-Daschle bill would extend these protections to groups so that predictive genetic information of one individual may not be used either to deny benefits to, or to raise premiums for, an entire class of people. It extends protections to those in the individual market. Predictive genetic information could not be used to deny coverage and it prohibits all health insurers from using predictive genetic information to increase premiums. It would provide not only tighter restrictions on the collection and disclosure of genetic information but also stronger enforcement authority. In addition, the Slaughter-Daschle bill would prohibit the use of predictive genetic information in employment.

HHS has been working with Congress for some time to develop measures that would protect the confidentiality of medical information, including genetic information. The **HIP** AA provided that, if legislation for the protection of individually identifiable health information was not enacted by August of 1999, the Secretary of HHS must promulgate regulations to provide such protection. Because Congress did not pass legislation by that date, we began the process of promulgating the regulation. A notice of proposed rulemaking was published on November 3, 1999, and the comment period closed on February 17, 2000. HHS received just under 52,000 comments which are currently being analyzed so that a final rule may be written. The President and I have made it very clear that one of our highest priorities is the enactment of a health information privacy bill that ensures comprehensive protections, since the authority provided in **HIP** AA is more limited in scope than the Federal statute that we recommend.

The President and I remain committed to working with Congress so that a bill protecting against genetic discrimination can be signed into law.

Sincerely,

A handwritten signature in black ink, appearing to read 'Donna E. Shalala', with a long horizontal flourish extending to the right.

Donna E. Shalala