DEPARTMENT OF HEALTH & HUMAN SERVICES Public Health Service

Secretary's Advisory Committee on
Genetics, Health, and Society
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June 27, 2003

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

Dear Secretary Thompson:

On behalf of the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS), I am writing to commend you and the President for advocating Federal legislation to prohibit discrimination in health insurance and employment on the basis of genetic information. Such legislation is a national priority, and we urge you to continue to do everything you can to ensure that comprehensive, uniform legal protections against the misuse of genetic information are enacted as soon as possible.

As you know, SACGHS met this month for the first time. One of the central goals of our inaugural meeting was to identify high priority issues that warrant immediate attention and action. During our two-day meeting, we heard a number of expert presentations on a wide range of issues raised by genetic technologies. We also received comments from the public. These briefings and wide-ranging perspectives affirmed the profound effects that genetic technologies are having on health and society and showed how their impacts will continue to grow as the technologies are enhanced and further developed. Our briefings and deliberations also demonstrated that people are generally very hopeful about genetic technologies and that they believe these technologies will lead to improvements in human health and many benefits for society.

At the same time, it is clear that genetic information can be used in unfair, unjust and harmful ways and that people are very fearful of such misuse. These fears are discouraging people from participating in genetic research and from undergoing genetic testing beneficial to their health care. They are causing people to pay out-of-pocket for genetic tests to prevent their test results from entering their medical records. Quite simply, these widely held fears are preventing people from taking advantage of the benefits that genetic technologies offer and hindering further advances in genetic research and test development.

After considering all that we heard about the many issues raised by genetic technologies, the Committee came to the unanimous conclusion that taking steps to prevent genetic discrimination in health insurance and employment must be our highest priority and first action item. We received a detailed briefing on Senate Bill 1053, the Genetic Information Nondiscrimination Act of 2003, from the majority staff in the Senate Committee on Health, Education, Labor, and Pensions (HELP). This bill, as you know, was

approved by the HELP Committee in May and is to be considered by the full Senate in the near future. We concluded that S.1053 will provide the needed protections against misuse of genetic information in health insurance and employment and will do so in a way that health insurers and employers can support. Indeed, we know firsthand that this bill has the support of a number of large health insurance companies. We are also aware that the Board of the American Association of Health Plans, a trade association representing more than 1,000 health plans that provide health care coverage to approximately 170 million Americans, has endorsed a set of principles that are consistent with the provisions of S.1053.

This year, the Nation celebrated the 50th anniversary of the discovery of the structure of DNA and of the completion of the international human genome sequencing project. To fully reap the benefits of these scientific milestones, we must put all of our efforts toward bringing our legal frameworks into the 21st century so that we can end the public's fear of genetic discrimination in health insurance and employment and enable Americans to enjoy the promise of the genetics revolution.

We commend the support you gave to S.1053 on behalf of the Administration, and we urge you to continue to press for similar action in the full Senate and the House of Representatives. Please know that SACGHS stands ready to be of service to you in any way we can to help the Genetic Information Nondiscrimination Act of 2003 become law.

Sincerely,

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