



Secretary's Advisory Committee on
Genetics, Health, and Society
6705 Rockledge Drive
Suite 750, MSC 7985
Bethesda, MD 20892-7985
301-496-9838 (Phone)
301-496-9839 (Fax)
<http://www4.od.nih.gov/oba/sacghs.htm>

May 3, 2005

The Honorable Michael O. Leavitt
Secretary of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Leavitt:

I am writing on behalf of the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS) to urge you to use your considerable influence to bring about the enactment of Federal legislation prohibiting genetic discrimination in health insurance and employment. To date, the Senate has passed a bill to limit the use of genetic information in health insurance and employment and the Administration has issued a strong statement in support of the bill. A companion bill is now pending in the House of Representatives, and we seek your assistance in moving this bill forward.

SACGHS was established in September 2002 as a forum for the exploration of the broad range of health and societal issues raised by the development and use, as well as potential misuse, of genetic technologies. From our first meeting, public concern about the potential misuse of genetic information in health insurance and employment has emerged as the highest priority of the Committee. Given action in the Senate and House on this issue, there is an immediate and compelling opportunity to press for passage of Federal legislation to prohibit genetic discrimination in health insurance and employment. Over the last several months, we have gathered key stakeholders' perspectives on this issue, including those from consumers, health professionals, researchers, health insurers, and employers. What we learned through these discussions obligates us to request your intervention on behalf of the public.

The Committee was influenced above all by the views and concerns we heard from patients and the general public. Their testimony made it abundantly clear that there are deep-seated fears about the potential for misuse of genetic information in health insurance and employment and that the public is concerned about the lack of specific Federal legal protections against genetic discrimination. Moreover, the public testimony documented that in many cases, healthcare decisions are being shaped by fear rather than best medical practice. We heard examples of patients seeking genetic testing outside the formal health care system, sometimes even at the suggestion of their own healthcare provider. Some are requesting that their test results be kept out of their medical records, while others are opting for anonymous testing. Yet others are forgoing testing altogether. The public testimony was clear and consistent about the need for Federal legislation prohibiting discrimination in health insurance and employment based on a person's genetic risk.

In keeping with our mandate to advise you about genetics issues affecting society, we believe it is both important and timely to convey this consensus opinion to you on behalf of the public. The enclosed video of excerpts from the testimony presented at our meeting of October 18, 2004 reflects the intensity of the public's concerns, as does the enclosed compilation of public comments we have received on this issue. We also heard from the Coalition for Genetic Fairness, an advocacy organization for this legislation which is comprised of representation from patient advocacy organizations, industry, and health professional societies. We were impressed by the arguments they made for Federal genetic nondiscrimination legislation as well as their approach to consensus building with other stakeholders.

In addition, we received testimony from, and held several follow-up meetings with, representatives of the business and health insurance communities. Through these meetings, we learned that, although clearly opposed to genetic discrimination, these stakeholders have reservations about various aspects of the legislation currently before the Congress. For example, America's Health Insurance Plans (AHIP) is concerned that legislation could prevent patients from receiving the best available treatments in a timely manner and that it could add more litigation to a system in which health care quality already suffers under the threat of lawsuits. As the enclosed letter to Congress from AHIP demonstrates, AHIP's views on the current legislation are complex and deserve your analysis.

The Chamber of Commerce provided valuable input on the perspectives of a large segment of the business community. The Chamber reported that employers are not engaging in discriminatory practices based on genetic information and expressed a number of concerns about the proposed Federal legislation. For example, the Chamber believes that current law appropriately protects the confidentiality of medical information and that a new law could increase employer exposure to frivolous lawsuits. While recognizing that the fear of potential discrimination may warrant a legislative solution, the Chamber maintains that the legislation should be aimed at reducing employee fears rather than addressing past discrimination. Like AHIP's views, the Chamber's views on the legislation are complex and also deserve your analysis.

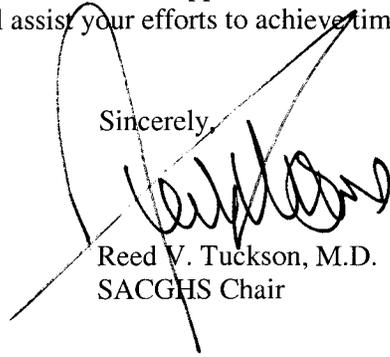
In fact, the Committee would ask you, in an effort to advance consensus-building, to invite these three key stakeholder groups--the Coalition for Genetic Fairness, AHIP, and the Chamber of Commerce--and any other interested parties that you may identify to come together to discuss with you their perspectives and positions on enacting Federal genetic nondiscrimination legislation.

The adequacy of current law in protecting against genetic discrimination is a critical part of the debate about the need for new Federal legislation. As such, SACGHS commissioned an analysis of the adequacy of current law which benefited from technical assistance from the Department of Justice, Department of Labor, Equal Employment Opportunity Commission, and, within the Department of Health and Human Services, the Office for Civil Rights and Centers for Medicare & Medicaid Services. The analysis, which is enclosed, reaches the following conclusions:

- There are no Federal laws that directly and comprehensively address the issues raised by the use of genetic information;
- There are laws and court decisions that address parts of these issues, but they leave substantial gaps in coverage and offer uncertain and inconsistent safeguards at best; and
- Current avenues for relief are uncertain and, if pursued, are likely to lead to confusion for consumers, insurers, and employers, as well as costly litigation.

In summary, the evidence before SACGHS compels us to urge you and the Administration to exert your influence and leadership to bring about the enactment of Federal legislation to prohibit genetic discrimination in health insurance and employment. Moreover, the Senate's unanimous passage of the Genetic Information Nondiscrimination Act of 2005 (S. 306) in February and the introduction in March of the companion bill (H.R. 1227) in the House provide propitious opportunities to accomplish this objective. We commend the Administration's overall support for Federal nondiscrimination legislation and hope that the enclosed materials will assist your efforts to achieve timely enactment of appropriate legislation.

Sincerely,

A handwritten signature in black ink, appearing to read "Reed V. Tuckson", is written over the word "Sincerely," and the typed name below. The signature is fluid and cursive.

Reed V. Tuckson, M.D.
SACGHS Chair

Enclosures

Tab A: Compilation of Public Comments and Video

Tab B: Letter from AHIP to the Honorable John Boehner

Tab C: Legal Analysis