



AMERICAN ASSOCIATION FOR THE
ADVANCEMENT OF SCIENCE

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October 14, 2003

The Honorable Dennis J. Hastert
Speaker of the House
H-232 Capitol Building
Washington, DC 20515

Dear Mr. Speaker:

On behalf of the American Association for the Advancement of Science (AAAS), I am writing to bring to your attention the conclusions of a AAAS working group concerning the need to protect against genetic discrimination.

The completion of the human genome sequence has raised hopes of a medical revolution, but to take full advantage of this momentous achievement, we must ensure the highest levels of public confidence that genetic information will be used appropriately to improve health and not to discriminate unfairly against people. The Senate has taken a great stride toward this goal by passing S. 1053, the Genetic Information Nondiscrimination Act, which is consistent with the conclusions of our working group. AAAS encourages the House to consider similar action.

The working group released a statement in 1999 which included the following conclusions:

- Individuals should be able to gain information about their genetic makeup, but should be able to protect themselves against discrimination by controlling access to such information.
- Genetic information should be used only to enhance, not undermine, an individual's quality of life. Society, therefore, in pursuit of the common good, has a responsibility to protect citizens against the misuse of genetic information.
- Policies should be adopted to ensure opportunities for people to participate in research studies and clinical trials without fear that their genetic information could adversely affect their health insurance status.

Founded in 1848, AAAS has worked to advance science for human well-being through its projects, programs, and publications, in the areas of science policy, science education and international scientific cooperation. The Association and its journal, *Science*, report nearly 140,000 individual and institutional subscribers, plus 272 affiliated organizations in more than 130 countries, serving a total of 10 million individuals. Thus, AAAS is the world's largest general federation of scientists.

The complete working group statement is available on the AAAS website at www.aaas.org/spp/dser/bioethics/resources/gdiscrim.shtml. For further information, please do not hesitate to contact Joanne Padrón Carney of the AAAS Center for Science, Technology, and Congress at 202/326-6798, or you may call my office.

Sincerely,

Alan I. Leshner