



July 20, 2004

The Honorable Sam Johnson
U.S. House of Representatives
1211 Longworth House Office Building
Washington, DC 20515

Dear Representative Johnson:

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 as it deliberates on H.R. 1910.

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.

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Founded in 1848, AAAS is the world's largest general scientific society and publisher of the journal, *Science*. The Association serves some 262 affiliated organizations in more than 130 countries, serving some 10 million individuals. The non-profit AAAS is open to all and fulfills its mission to "advance science and serve society" through initiatives in science policy and more.

The complete genetic discrimination working group statement is available on the AAAS website at <http://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,

A handwritten signature in black ink, appearing to read "Alan I. Leshner". The signature is fluid and cursive, with a large initial "A" and "L".

Alan I. Leshner



July 20, 2004

The Honorable Robert E. Andrews
U.S. House of Representatives
2439 Rayburn House Office Building
Washington, DC 20515

Dear Representative Andrews:

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.

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