



AMERICAN ASSOCIATION FOR THE  
ADVANCEMENT OF SCIENCE

*Advancing science • Serving society*

March 21, 2003

The Honorable Bill Frist  
Senate Majority Leader  
SR-416 Russell Senate Office Building  
Washington, DC 20510

Dear Senator Frist:

As the 50<sup>th</sup> anniversary of the discovery of the DNA double helix approaches, I would like to bring to your attention the attached statement released by an American Association for the Advancement of Science (AAAS) working group in 1999 concerning the need to protect against genetic discrimination.

The completion of the human genome sequence has raised hopes of a medical revolution that will lead to major health advances. However, to take full advantage of this momentous scientific achievement, we must ensure the highest levels of public confidence that the genetic knowledge gained about individuals and groups will be used appropriately to improve health and not to discriminate unfairly against people.

The 1999 statement 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.

As the Senate considers legislation to address these issues, AAAS stands ready to assist you in any way possible. 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

Enclosure



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**STATEMENT ON GENETIC DISCRIMINATION IN HEALTH INSURANCE**  
AAAS Program of Dialogue on Science, Ethics, and Religion

November 1999

In 1995, the American Association for the Advancement of Science (AAAS) established a Program of Dialogue Between Science and Religion (renamed in 1999 as the Program of Dialogue on Science, Ethics, and Religion) in order to improve communication and understanding between the two fields. Since the Program's creation, several dialogue meetings have been held to explore the spectrum of religious and scientific thinking on issues related to advances in our knowledge of genetics and to promote thoughtful dialogue and a search for common understanding of their ethical, theological, and social implications.

Out of these meetings, there has emerged a genuine, collective concern about the possible discriminatory uses to which genetic information may be put, particularly in those cases where a genetic disease or a predisposition to disease is identified. This is a matter of considerable public concern in the context of health insurance and access to medical care. The timing seems right for voices in the scientific and religious communities to join with others in addressing these matters. A Dialogue Group began meeting in 1996 to consider these specific issues. The Group's members include academic scientists, ethicists, and theologians, religious leaders of different faiths, and representatives from consumer and patient advocacy groups, government, and the pharmaceutical and biotechnology industries. The following Statement is a product of the Group's dialogue on genetic discrimination in health insurance in those instances where there is a predisposition to disease without a diagnosis of a specific illness.

The power and potential of predictive genetic tests is the knowledge they provide. It is important to recognize that such knowledge is probabilistic and must be properly understood not only by individuals being tested, but also by family members, employers, schools, insurers, and legal and medical institutions. The AAAS Dialogue Group reaffirms the great value of genetic research. However, the knowledge gained is sometimes a double-edged sword. On the one hand, knowledge of one's predisposition to a genetic disorder opens up the possibility of prevention or treatment of disease. On the other hand, the results of genetic testing could be used to classify people according to specific genotypic characteristics that may subject them to discrimination and stigmatization as individuals and/or members of a group. Health insurance is one venue in which genetic discrimination might occur. People who undergo genetic testing and are found to be at risk for a disease or condition could have the scope of their health insurance coverage restricted, or could be forced to pay exorbitant premiums to retain their insurance. Others might refuse to undergo testing out of fear of discrimination. Still others might decline participation in research studies for fear that the information gained through genetic testing would be used against them by insurers. Neither threats of nor actual discrimination based on genetic information should be allowed to impede access to therapies based on the discoveries of such genetic research or the ability and willingness of persons to participate in critical studies.

The AAAS Dialogue Group believes that science and religion can make useful contributions to the public discussion of these issues. Its members embrace five principles relevant to these discussions: (1) that our political and religious traditions recognize all humans as beings of equal worth and inherent dignity, and these traditions should not be undermined by genetic differences; (2) that individuals should be able to gain access to information about their own genotypes; (3) that individuals may

protect themselves against discrimination by controlling access to information about their genotypes; (4) that society, in pursuit of the common good, has a responsibility to protect citizens against the misuse of genetic information; and (5) that individuals and society should support research in genetics that, using legitimate means, aims to alleviate suffering associated with illness.

We have elaborated upon these principles with respect to current policy debates on the uses of predictive genetic test results in health insurance, and present these ideas below:

- We acknowledge the universal nature of genetic variation. As a consequence, we all have an interest in ensuring that genetic information is not used to discriminate against or otherwise bring harm to any individual. The information should only be used to enhance, not undermine, the quality of one's life.
- We recognize the importance of research in developing effective remedies for incurable and untreatable diseases and the great value of contributing to the bank of scientific knowledge.
- We urge the adoption of policies that ensure opportunities for people to participate in research studies and clinical trials without fear that the information generated by their participation will be inappropriately disclosed and adversely affect their health insurance status or that of their families, either as individuals or as members of a particular group.
- We urge that identifiable medical information, which may in some instances include more than a person's name, not be disclosed without a person's prior authorization except in accordance with applicable law. Patient confidentiality policies should recognize that medical information and genetic information are inextricably linked. Public policy should not perpetuate unscientific and artificial distinctions between the two.
- We support distinguishing anonymous medical information from patient/subject identifiable information in order to protect individuals' rights while furthering promising research. The anonymized information should be freely accessible for legitimate and ethically approved research purposes, while identifiable information should be subject to more restrictive requirements for gaining access.

The AAAS Dialogue Group offers this Statement as a contribution to the on-going public debate in the hope of protecting Americans from discriminatory practices in health insurance based on the use of genetic information produced by predictive testing. We realize that the positions reflected in this statement raise critical challenges for our health care system and insurance providers, such as that of adverse selection, but we call upon the scientific and religious communities - indeed, on all people of good will - to bring an informed understanding and a generous heart to this debate. Both public policy and justice are better served if public discourse on these issues is scientifically grounded and if people appreciate the promise of genetic knowledge and the human consequences of its uses.

### **Signatories\***

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\*The listing of affiliations is for informational purposes only; it does not necessarily mean endorsement by any organization listed.