

May
8,
2002

The Honorable Edward M. Kennedy
Chairman
Committee on Health, Education, Labor and Pensions
United States Senate
Washington, DC 20510

Dear Mr. Chairman:

On behalf of the more than 60,000 biomedical research scientists represented by the Federation of American Societies for Experimental Biology (FASEB), I am writing to urge the Senate to pass legislation this year to protect Americans from genetic discrimination by insurers and employers.

The mapping of the human genome has unveiled a vast, new wealth of information. This data will one day reveal every person's genetic predisposition to a variety of differing diseases. It can be used as an important tool to prevent and treat disease. It can also be misused as a weapon to discriminate against individuals.

We are concerned about the chilling effect on biomedical research that is likely to occur in the absence of enhanced protections against genetic discrimination and the resulting loss of scientific knowledge. FASEB believes that a growing number of Americans will be discouraged from participating in vital research for fear of employment and health insurance-related consequences associated with the release of their genetic information to their employers or health insurance providers. As you know, biomedical advances are dependent on the willingness of individuals to participate in clinical research. Current law does not provide sufficient protection against job loss, health insurance cancellation or denial of coverage as a result of genetic discrimination.

We understand that there are many more areas of consensus than disagreement between alternative bills, and we urge you to bridge the gap to pass a basic level of nondiscrimination protection for all Americans.

We thank you for your invaluable leadership on this, and many other important health and medical issues, and urge you to act this year to set a floor of basic protections for all Americans from genetic discrimination.

Sincerely,

Robert R. Rich
President