



BIOTECHNOLOGY  
INDUSTRY  
ORGANIZATION

May 19, 2003

The Honorable Judd Gregg  
Chairman  
Senate Committee on Health, Education, Labor and Pensions  
835 Senate Hart Office Building  
Washington, DC 20510

The Honorable Edward M. Kennedy  
Ranking Minority Member  
Senate Committee on Health, Education, Labor and Pensions  
644 Dirksen Senate Office Building  
Washington, DC 20510

Dear Senators:

As President of the Biotechnology Industry Organization (BIO), an organization that represents more than 1,000 biotechnology companies, academic institutions, state biotechnology centers and related organizations that are involved in the research and development of health-care, agricultural, industrial and environmental biotechnology products, I am writing to express my support for your efforts to enact legislation this year that will prohibit health insurers from discriminating against individuals based on genetic information.

I understand progress has been made toward an agreement on a bi-partisan bill and I urge you to resolve any remaining outstanding issues.

We have all been dazzled over the past few years at the pace of scientific discovery. Last month came the latest announcement about the completion of the sequencing of the human genome. Over the next several years, even more will become known about how our bodies develop, function, and change.

This information will be enormously powerful. Armed with these data, scientists might soon be able to identify genetic causes of disease and learn about genetic factors affecting cellular development and function.

Understanding the function of genes in key biological processes will also become an even bigger part of drug discovery and development. This information could, for

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example, tell us how and why certain diseases afflict certain people and why certain medications are safe and effective for some people, but not others with the same diagnosis.

Thus, genomic information could speed the development of cures and treatments for illnesses that afflict millions of Americans and their families.

However, public fear and anxiety are obstacles to achieving this goal. That's why BIO supports federal legislation prohibiting inappropriate use of genetic information by health insurers.

People must have confidence they can take advantage of technological developments without fear that the information gained from this technology will be used against them. For example, with the information individuals could get from genetic tests, they could take steps – such as improving their diet, avoiding certain drugs or foods, and getting preventive medical care – that are likely to improve their health. However, if individuals believe that this information will cost them their health insurance, they may not seek it.

BIO has long supported national policies to ensure that individuals' personal medical information, including genetic information, is safeguarded against misuse. It is essential to assure the public that the great promise of biotechnology research will not be tarnished by abuses of this technology.

Consequently, BIO supports carefully drafted legislation prohibiting discrimination in health insurance based on genetic information. Based on our reading, your proposal meets this criterion and BIO stands ready to work with you and your colleagues to help get it enacted. If you have any additional questions about BIO's views on this matter please call either me or Michael Werner, BIO's Vice President for Bioethics at 202-962-9200.

Sincerely,

A handwritten signature in black ink, appearing to read "Carl B. Feldbaum", with a long horizontal flourish extending to the right.

Carl B. Feldbaum

President

Biotechnology Industry Organization

CBF:ks