

cases against two others who have pleaded not guilty to similar charges: Takeshi Abe, who headed the Health and Welfare AIDS research team in the 1980s, and Akihito Matsumura, a former ministry official.

The Japanese government and Green Cross have also agreed to compensate nonhemophiliacs who became infected with HIV through contaminated blood products. An out-of-court settlement,

recommended by the Osaka district court is the first agreement to compensate such individuals. Each plaintiff will receive a one-time payment of ¥45 million (US\$360,000) and lifetime financial support. The settlement follows an agreement last March between the government, Green Cross and four other pharmaceutical companies, and hemophiliacs infected with the virus (*Nature Medicine* 2, 498; 1996).

According to Ministry of Health and Welfare figures, approximately 2600 non-hemophiliacs were given non-heat-treated blood products in the 1980s. Of these, 11 people were infected with the virus. More than 60 percent of all Japanese people in Japan who are HIV-positive were exposed to the virus through contaminated blood products.

RICHARD NATHAN  
Tokyo

## Genetic privacy bill "may hinder research"

A bill before Congress that seeks to protect people's genetic privacy has run into unexpected opposition — from members of the science and biotechnology communities. Although scientists strongly support the section of the bill that aims to prevent genetic discrimination in the workplace — the only bill so far before Congress that covers this topic — they fear that other elements of the bill that seek to define genetic information as different from all other medical records could seriously hamper research.

The bill, introduced by Senator Pete Domenici (R-New Mexico), would preclude employers from requesting genetic information from their employees. Scientists welcome this move, and few doubt that it is needed, as tests to detect mutations that predispose to diseases such as Huntington's and breast cancer become widely available. However, a second section of the bill would require anyone having access to a patient's genetic information, such as doctors and scientists, to seek authorization to use the information in any way. This authorization would be separate from the normal permission sought to use general medical records.

This approach is unworkable and unrealistic, say researchers. "All disease has a genetic basis," says Francis Collins, director of the National Human Genome Research Institute. "It is not practical or desirable to separate genetic information from other health information."

His sentiments are echoed by Carl Feldbaum, president of the Biotechnology Industry Organization, which represents 700 biotechnology companies and academic institutions. "We are forced to oppose the Domenici bill in its present form,"

says Feldbaum, "because it does not include any other sorts of medical information that can also be used as a basis for discrimination and it unfairly stigmatizes genetic information." Medical research would suffer because scientists would have to seek special permission from patients to use any clinical tissue sample, including stored samples obtained many years ago, for DNA analysis. "Separating genetic information will be difficult to define and administer either in the research environment or in medical practice," says Lyle Dennis, director of the Genome Action Coalition, a group of more than 100 patient advocacy and professional groups, as well as pharmaceutical and biotechnology companies.

Ironically, the Domenici bill was introduced only days before the publication in the journal *Science* (275, 1755; 1997) of a set of recommendations designed to help federal and state lawmakers considering legislation to prevent genetic discrimination in the workplace. These recommendations — drawn up by the Working Group on Ethical, Legal and Social Implications of Human Genome Research (ELSI) and the Hereditary Susceptibility Working Group of the National Action Plan on Breast Cancer (NAPBC) — include prohibiting employers from requesting genetic information or from using such

information to deny individuals a job or to fire them, restricting the access of employers to an employee's genetic records, seeking the written consent of employees for each disclosure of genetic information, and ensuring the right to bring legal action against violators.

There are already reports of discrimination by employers, such as the case of Christine DeMark, from Milwaukee, Wisconsin. DeMark's mother died of Huntington's disease. When DeMark was tested and found to be carrying the mutation for the disorder, she lost her job, even though the genetic test cannot predict the age of onset, progression or severity of this condition.

While the problems with the Domenici bill continue, other legislation was due to be introduced into Congress late last month. In contrast to its predecessor, this legislation is based on the ELSI-NAPBC recommendations. A bill drafted by Nita Lowey (D-New York) and Rick Lazio (R-New York) addresses genetic discrimination in the workplace. Another, to be introduced by Senator Connie Mack (R-Florida), seeks to protect the confidentiality of genetic records. A counterpart to the Mack bill is planned for the House of Representatives.

ORLA SMITH

## Former prime minister to stand for top WHO post

Gro Harlem Brundtland, Norway's former prime minister, has announced that she is willing to stand for election for the post of director-general of the World

Health Organization. The UN agency's executive board, made up of health specialists from member states, will vote on the appointment next January.