

# House backs curb on genetic information

**Washington.** The US House of Representatives last week passed a bill preventing health insurers from using genetic information to exclude potential clients, a move that many researchers say is needed to reassure volunteers for genetic screening programmes. The new prohibition is part of a large health reform bill designed to improve insurance portability.

But the Republican-authored bill includes many other controversial provisions that could prevent it from becoming law. Among these are plans to limit damages in medical malpractice suits, to allow individuals to set up tax-deductible 'medical savings accounts' to pay for routine health care, and to curb the regulation of insurance plans by state authorities.

The Senate has already drawn up a less ambitious bill, which has received broad bipartisan support. This has prompted Democrats to allege that Republicans in the House are merely trying to sabotage the more politically viable Senate legislation with their more radical version, approved on 28 March on a largely party-line vote.

Amid the larger controversy, the reference to genetic information was inserted in the House bill late last month "under the



radar", says Lyle Dennis, director of the Genome Action Coalition, which is seeking a prohibition on the use of genetic information in both bills.

The House bill, like its Senate counterpart, would prevent insurers from denying coverage to employees when they change or lose jobs. It would guarantee continued coverage to those becoming ill. It states that insurers may not use 'health status' to bar people from coverage, and — unlike the Senate bill — defines this to include "genetic information."

"These two words make a good piece of legislation better," said Clifford Stearns (Republican, Florida), a key backer of the House provision, in a written statement. Those observing the issue from the National Institutes of Health (NIH) agree. "We are

very pleased," said Kathy Hudson, assistant director for policy at the National Center for Human Genome Research.

The insurance industry, however, claims that such a measure is unfair. In a voluntary marketplace, where many products are individually underwritten, companies "should have the same access to [genetic] information as the applicant", says Harvie Raymond, an assistant vice president at the Health Insurance Association of America.

Meanwhile, others are concerned that, even if controls on the use of genetic information are included in a bill that becomes law, insurers would remain free to demand

high prices for those who show genetic predisposition to disease. "That's a big loophole," says Neil Holtzman, director of genetics and public policy studies at the Johns Hopkins Medical Institutions in Baltimore, Maryland.

Holtzman chairs a task force on genetic testing of the NIH/Department of Energy Working Group on Ethical, Legal, and Social Implications of Human Genome Research (ELSI), which last month released draft principles endorsing a 1995 report from another ELSI working group that insurers be barred from using genetic information to discriminate. **Meredith Wadman**

## Anthropologist cleared in patent dispute

**San Francisco.** The government of Papua New Guinea last week backed off allegations of wrongdoing against an anthropologist, Carol Jenkins, who has been at the centre of a row over the patenting by the US government of a cell line derived from the Hagahai people of Madang Province.

In doing so, it shelved any efforts to deport Jenkins, and agreed that her research had been conducted with the full consent of the Hagahai people, and that its benefits were intended to be shared among all concerned. At the same time, Jenkins has agreed to help government officials draw up a policy on the appropriate legal framework for research on indigenous populations.

Last month, Jenkins, a principal research fellow with the Papua New Guinea Institute of Medical Research who is involved in aid intervention research in the central highlands of Papua New Guinea, was escorted off a plane from Port Moresby that was heading to a meeting of the World Health Organization in El Salvador, and asked to explain her activities.

As she prepared last week to meet with Gabriel Dusava, Secretary for Foreign Affairs and Trade, it seemed that she might be deported. But after a long discussion, Dusava cleared her of any wrongdoing. In a subsequent press release, he emphasized that the meeting had resulted in an understanding of "the need for close government and research personnel co-operation in sensitive areas of research [such as] human blood and viruses, where formal frameworks are not available to set principles and regulations."

Jonathan Friedlaender, professor of biological anthropology at Temple University in Philadelphia, and a past director of the National Science Foundation's

physical anthropology programme, said that although the whole incident had been painful for Jenkins, it should help resolve conflicts over the social and ethical issues surrounding the patenting of modified DNA fragments taken from human subjects.

The US Patent Office issued a patent on the Papua New Guinea human t-lymphotropic virus (HTLV-I) to the Department of Health and Human Services in March 1995. It was the first human cell line taken from an indigenous population ever to be patented.

In an informal agreement, Jenkins, who as co-inventor was entitled to 50 percent of the royalties from any resulting commercial products, assigned her entire share to the Hagahai people. She says that she had discussed the matter with the Hagahai leaders, and that had jointly agreed that patenting would be the best approach.

At the time, scientists familiar with the research told newspapers that the likelihood of any commercial product being based on the cell line was slight, but that it might conceivably be used in a test for the variant virus, or to develop a vaccine. Nevertheless the patent claim outraged groups such as Rural Advancement Foundation International in Canada, a keen opponent of patents on living organisms — including humans.

Jean Christie, director of international liaison for RAFI, said the organization did not dispute Jenkins' intentions, but that major policy issues remained unaddressed. She said that Jenkins' agreement to work with the Papua New Guinea government was a positive step toward a major international debate over informed consent and patenting. But RAFI still insists that human genetic material and any other living organisms should not be patentable. **Sally Lehrman**