

DNA needs to be protected by law

Zosia Kmietowicz *London*

The United Kingdom's genetics watchdog has hinted that the only way to prevent someone getting hold of another person's genetic information without their knowing may be to make DNA theft a criminal offence.

Members of the Human Genetics Commission have said that when they present a report to ministers in April there is a "strong possibility" that one of their key

recommendations will be to make it illegal for someone to obtain a sample of cells from another person and submit it for genetic testing without their consent.

Baroness Helena Kennedy, chairwoman of the commission, said: "People are leaving information around wherever they go. Once it is clear how readily one can pick up that information about people you realise how serious this matter is."

A piece of hair, a nail clipping, or a swab from a glass of beer could all be used to provide information without the person concerned ever knowing. Fathers or mothers in law concerned about the paternity of their children or grandchildren could quite easily

obtain samples of cells without the child or its mother being told, said Baroness Kennedy.

At the moment all UK testing companies have a voluntary code not to perform a test on a sample without the mother's consent, she added. But that does not prevent people sending samples abroad—hence the need for protection, probably by the creation of a new law.

The commission is also looking at how genetic information obtained by the police and through research should be stored and used. Professor Alexander McCall Smith, professor of medical law at Edinburgh University and vice chairman of the commission, said that another

important consideration was to ensure that genetic information collected for research purposes was "absolutely watertight in terms of security."

There is a real sense of "genetic solidarity" among the public, said Baroness Kennedy, and people are keen to take part in research "as long as they feel it is for the general wellbeing of society and that there are adequate protections." She said that people want "the reassurance that their goodwill is respected and they will not be putting themselves at risk of exploitation. Our challenge is to build on that goodwill without allowing people to have their trust betrayed." □

Proposed genetic database on Tongans opposed

Bob Burton *Canberra*

A proposal by a Melbourne based biotechnology company, Autogen, to establish a database of genetic information on the population of Tonga in the South Pacific is floundering after opposition from church and pro-democracy groups.

In November 2000 Autogen triumphantly announced to the Australian Stock Exchange that it had signed an agreement with the Tongan health ministry to undertake a project "aimed at identifying genes that cause common diseases using the unique population resources in the Kingdom of Tonga."

The project is the product of an alliance between Autogen and Merck Liphra, a subsidiary of the German pharmaceutical giant Merck. Merck holds a 15% stake in Autogen and is funding a six year research programme to identify genes associated with obesity and diabetes.

Autogen's chairman and largest shareholder, Joseph Gutnick, is a confidante of former prime minister of Israel, Benjamin Netanyahu, while another director is former Australian Labor party prime minister, Bob Hawke.

While the company's board boasts some political heavy hitters, it failed to anticipate that the secretly negotiated agreement would encounter opposition from those advocating a more accountable government in the Pacific's only remaining monar-

ch. Autogen's statement on ethics emphasised prior informed consent of individual volunteers but remained mute on the traditional Tongan role of the extended family in decision making. "We want to also add the prior informed consent of the extended family... because what we are talking about is not only the genetic information from that one individual but the genetic material from that extended family," Mr Senituli said.

At the request of Mr Senituli, the professor of health law at

Nor did Autogen anticipate that its proposal would spark regional opposition. In March 2001 a major conference on bioethics hosted by churches from the Pacific resolved that no government should sign agreements before there had been extensive public consultation. They also objected to the conversion of God-created "life-forms, their molecules or parts into corporate property through patent monopolies."

The chief scientific officer of Autogen, Professor Greg Collier, insisted that the company had no immediate plans for research work in Tonga and was concentrating its resources in the Australian state of Tasmania: "In Tasmania it is easier for us to find families and work with them more easily."

Mr Senituli doubts the company has really retreated: "What intrigues us is why Autogen has not removed the reference to Tonga from its website—why has the stock exchange not been told? This is what worries us."

Professor Collier has no intention of removing the website reference to the Tonga proposal or of issuing a clarifying statement to the Australian Stock Exchange pronouncing the proposal dead: "There is no changing that... it would look more like to me that we were covering our tracks." □



Autogen's emphasis on the prior consent of individuals did not take into account the role of the extended family in Tonga

chy. The Director of the Tonga Human Rights and Democracy Movement, Lopeti Senituli, objected to being presented with a fait accompli: "We expressed opposition to it primarily because there was no public discussion."

Boston University School of Public Health, Dr George Annas, reviewed Autogen's ethics policy. In correspondence he described it as "unacceptably vague" and having "no enforcement mechanism whatsoever."