

# CALL OF THE EARTH LLAMADO DE LA TIERRA ISSUES IN INTELLECTUAL PROPERTY POLICY 5

## Indigenous Human Genetic Resources & Intellectual Property Policy

### The Issue:

The genetic information of Indigenous Peoples is sometimes of interest to scientific researchers, often due to distinct physiological features and historical isolation. In a number of cases, the way in which genetic information has been obtained has led to questioning of whether there was prior informed consent, who now 'owns' the information and what it can be used for.

This issue would raise ethical questions of profound consequence in any cultural context however given their frequent status as preferred subjects, it is in many cases Indigenous Peoples who have direct experience of the questions and consequences arising from genetic research. The following examples indicate the type of scenarios that have arisen in Indigenous Communities.

### Examples:

#### *Panama*

The genes of a Ngobe-bugle woman of Panama were patented by US researchers in the United States. The samples from which the genes were isolated were taken from the woman by researchers with the assistance of a local doctor. The genes relate to immunity to the HLV2 virus, an AIDS related virus to which the Ngobe-bugle display immunity. Spokespersons for the peoples involved suggest that they are happy to be involved in public interest research but object to the possibility of corporate profit making from their genetic resources. Following international pressure, the patent was abandoned. The cells remain in a United States laboratory.

#### *Tonga*

The people of Tonga are subject to an agreement signed between their government and a private corporation that grants the corporation exclusive use of a database of their genetic information. Autogen, an Australian company with connections to the pharmaceutical giant Merck, are interested in disease genes of the Tongan population, particularly those related to diabetes and obesity, and aim to commercialize discoveries. A statement of the Tongan National Churches suggests that peoples of the Pacific are the guardians of their heritage and should have the right to protect and control dissemination of that heritage, that Pacific peoples have the right to manage their own biological resources and protect them from expropriation and exploitation by scientific, corporate or governmental interests, and that the conversion of life-forms, their molecules or parts into corporate property through patent monopolies is counter productive to the interests of Pacific peoples. Although there has been civil society condemnation from groups such as the Tongan Council of Churches (as well as the World Council of Churches) and the Tongan Human Rights and Democracy Movement, the agreement stands.

## *Papua New Guinea*

The US Department of Health and Human Services and the National Institutes of Health patented a cell line from a Papua New Guinean Hagahai man in March 1994. Although the patent was abandoned in 1996, the cell line can still be accessed in the American Type Culture Collection for a fee.

### **Indigenous Perspectives:**

Indigenous Peoples are concerned that medical research can be exploitative when samples are taken without prior informed consent. Further, many Indigenous Peoples are concerned about proprietary rights that researchers, universities and corporations may claim over research results and product developments, both from the point of view of who gains from the genetics of Indigenous Peoples, and more fundamental questions relating to the ethics of patenting of life.

### **The Way Forward:**

Any Indigenous involvement in genetic research must have the prior informed consent of those involved. There is not yet any regulatory framework for supervision and enforcement of prior informed consent. This has been a largely ignored issue to which further attention could be given by the international human rights community.

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#### Notes

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