

# **The Human Genome Project and the Issue of Biodiversity**

*Priscilla Settee*

## **About the Author**

Priscilla Settee is a Cree Indian from northern Saskatchewan. She is Director of the Indigenous Peoples Program with the Extension Division at the University of Saskatchewan. Ms Settee is associated provincially, nationally and internationally with several boards and organizations. She has worked as an advisor to the International Development Research Centre (Ottawa) and helped produce the book *Seeding Solutions, Policy Options for Genetic Resources*. Settee works with NGO's in the South Pacific in building strategies for preserving biodiversity and Indigenous Knowledge. She has written a chapter called "The Issue of Biodiversity, Intellectual Property Rights, and Indigenous Rights" in the new Native Studies Textbook" *Expressions in Canadian Native Studies* (2000), of which she is a co-editor.

## **About the Article**

Priscilla Settee outlines the work of Aboriginal peoples around the world to mobilise against biopiracy – the appropriation of Indigenous knowledge, and Indigenous bodies. The focus of much of this mobilising has been the Human Genome Diversity Project – a DNA sequencing project proposed as a complement to the international Human Genome Project. The HGDP is distinct in being intended as a way to gather the DNA of 'diverse' or 'endangered' peoples and thereby to 'map the migration history of humankind.' While the official HGDP has been derailed by the protests of its many critics, biopiracy is alive and well and commercially lucrative. As Settee here explains, Indigenous peoples have organised around the HGDP to articulate their own priorities, and to formulate agendas for tackling the large and growing problem of biopiracy.

The Human DNA of identified Indigenous groups is the focus of curiosity and activity among an international consortium of scientists, universities, governments, and other interests in North America and Europe.<sup>1</sup>

Over 700 Indigenous groups world-wide have been identified to have samples collected from them. Indigenous communities targeted for DNA collection include Africa (165), Asia (212), South America (114), Oceania (101) North America (107 tribes) and Europe (23). Established in 1992, the Human Genome Diversity Project (HGDP) will take blood, tissue samples (cheek scrapings or saliva), and hair roots from hundreds of Indigenous communities throughout the world. Through the Human Genome Organization (HUGO) the project is mandated to map the entire genetic structure of the human race

HUGO seeks to sequence the DNA information in all 100,000 genes in the human body and is expected to cost 3 billion dollars over the span of the fifteen year project; HUGO is now nearing completion significantly ahead of schedule; a 'rough draft' has already been completed. While HUGO intends to uncover the norm of the human genome as a composite model, the Human Genome Diversity Project seeks to map and sequence genetic diversity. The project is specifically mandated to take blood, tissue, and hair samples from

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<sup>1</sup> This article draws on the following source material: Indigenous Women Address the World. *Indigenous Woman Magazine*. Special Beijing Edition, Rapid City, South Dakota, U.S.A. 1996; *Indigenous Woman Magazine*, Rapid City, South Dakota, U.S.A., Vol, 2, No. 3, 1996; Dukepoo, F., & Harry, D. Indigenous Peoples Coalition on Biopiracy, 1998; "Voice of Native Grassroots for Environmental Justice." *Indigenous Environmental Network News*. Vol.3 No. 2, 1997; *Western Shoshone Defense Project Newsletter*, 1997.

"endangered" indigenous communities around the world.

The HGD project was formally adopted in 1994 by the Human Genome Organization. It has sought massive funding. This multi-billion dollar initiative by scientists has plans to sequence the DNA in the entire human genetic structure. The HGDP seeks to map the genetic difference of groups from the monotype genome that will be identified by the HUGO effort.

Scientists believe that many of the world's Indigenous people are in danger of becoming extinct and refer to them as 'isolates of historic interest'. Scientists hope to gather DNA samples from the living before they disappear forever, and so avoid the irreversible loss of precious genetic information. Indigenous peoples find it reprehensible that scientists' interest is purely to document scientific genetic information rather than to preserve tribal groups. In effect, the scientists are asking endangered tribal groups to submit personal samples before their group disappears. The scientists' actions revive out-dated and oppressive attitudes, and their actions instil self-fulfilling pessimism. Such actions are simply unethical.

Blood samples taken from Indigenous peoples will become immortalized for future study. A technique called "cell conservation" will keep certain cells of an organism alive and capable of multiplying. Unlimited amounts of the organism's DNA will be stored at various gene banks, mostly in the United States.

Indigenous peoples have many concerns with the HGDP. One is the issue of informed consent. Although the HDGP claims that it will seek the consent of the individuals and populations concerned, many people doubt whether this will, in fact, happen. Some questions that remain unanswered are:

- Can tribal leaders give consent for the whole tribe?
- Can one person give consent while others don't?
- How can some of these concepts be explained in ways and languages for people who have no concept or words for these confusing terms?
- What are the benefits for the local communities?
- Will decisions to refuse consent be fully respected?

The HGDP North American Committee secured a grant to develop a model protocol or rules for the collection of samples from Indigenous groups. It is felt by Indigenous people that this protocol will primarily be used to seek project co-operation.

The HGDP states that the research will help reconstruct the history of the world's populations, address questions about the history of human evolution and migration patterns, and identify the origins of existing populations. While the HGDP is looking for answers about human evolution, Indigenous peoples already possess strong beliefs and knowledge regarding their creation and histories.

Danny Billie, traditional spokesman for the Independent Seminole Nation of Florida, stated in 1997

“The white people are trying to play God. If they continue to do what they are doing the impact to the human species, insects, plant and animal life is going to be devastating. They think that they can get away with it, but they'll also suffer the consequences.”

In response to the HGDP research Indigenous peoples from various parts of the world have mobilized against the project. Documents such as the Ukupseni Declaration from Panama and the National Congress of American Indians Resolution

No. 93-118 have been signed. These documents represent hundreds of communities who declare their opposition to the HGDP.

Karioca Declaration. In the early 1980's, the Karioca Declaration was signed by a group of Indigenous people who were opposed to the HGDP and who met prior to the 1993 United Nations Conference at the Earth Summit in Rio de Janeiro.

Mataatua Declaration. The Karioca Declaration was followed ten years later by the Mataatua Declaration and signed by over 150 participants from 14 United Nations countries. The Declaration calls for an immediate halt to the ongoing HGDP until all aspects of it could be understood by Indigenous peoples.

Article 29. In 1994 The United Nations' working group on Indigenous populations, along with the Sub-Commission on the Prevention of Discrimination and Protection of Minorities approved Article 29 of the Declaration of the Rights of Indigenous Peoples which stated:

“Indigenous Peoples are entitled to the recognition of the full ownership, control and protection of their cultural and intellectual property. They have the rights to special measures to control, develop and protect their sciences, technologies and cultural manifestations including human and other genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, and visual and performing arts.”

New Zealand. In 1993 an assembly of representatives of the tribes from the North and South Islands of Aotearoa (New Zealand) passed resolutions condemning the HGDP and the patenting of life-forms.

National Congress of American Indians. In that same year the National Congress of

American Indians (the oldest and largest national organization, comprised of representatives from 671 American Indian tribal governments in the United States) passed a resolution condemning the HGDP and called upon all related activities to cease immediately.

Central Australian Aboriginal Congress. Coined as the "Vampire Project" by the World Congress of Indigenous Peoples, the Central Australian Aboriginal Congress Position Paper stated in 1993:

"The Vampire Project is legalized theft. The Vampire scientists are planning to take and to own what belongs to Indigenous People. We must make sure that our people are not exploited once more by corporations, governments, and their scientists."

Maori Congress. In 1994 at the Maori Congress Indigenous Peoples Roundtable, Indigenous participants from the World Council of Indigenous Peoples, Greenland Home Rule Government, COICA (Peru), Treaty Six Chiefs of Alberta, and governmental representatives from Vanuatu, Papua New Guinea, and Fiji declared that:

"The collection of genetic samples from Indigenous peoples such as the Human Genome Diversity Project, is unethical and immoral and must be brought to an immediate halt."

Patents on Indigenous Peoples. Also in 1994 in Panama, the Guaymi Indians, along with citizens of Papua New Guinea and the Solomon Islands, discovered that the United States government had taken patent claims out on the cell lines from some of their people. Through effective campaigning they were able to have the patent claim abandoned.

Workshop on "Intellectual Property Rights". In August 1994, the International Academy of the Environment, along with

the World Wildlife Federation and the United Nations Centre for Human Rights, organized an information workshop on "Intellectual Property Rights and Indigenous Peoples" stating:

"The issue of HUGO, and others related to human genes, is a serious violation of our peoples' rights. Without consultation with the indigenous communities, several projects are now taking blood, hair, tissue and other samples for purposes that are not clear. This practice of collecting samples without our approval is very dangerous because in this way our genetic material can be patented or used for other purposes. Such practices not only violate ethics and human rights, but also violate nature, our spirituality, and our knowledge of creation that connects us with all forms of life."

Latin and South American Consultation. In Bolivia in September 1994, the Latin and South American Consultation on Indigenous Peoples Knowledge rejected the HGDP and human genetic research.

Asian Consultation. Similarly in Malaysia in 1995, the Asian consultation on the Protection and Conservation of Indigenous Peoples Knowledge rejected the HGDP.

Declaration of Indigenous Organizations. In Arizona, at the same time, Indigenous leaders from US, Canada, Panama, Ecuador, Peru, Bolivia, and Argentina, formulated a Declaration of Indigenous Organizations of the Western Hemisphere. It considered the responsibility to future generations:

"We have a responsibility to speak for all life forms and to defend the integrity of the natural order. We particularly oppose the HGDP which intends to collect, and make available our genetic materials which may be used for commercial, scientific and military

purposes. We oppose the patenting of all natural genetic materials. We hold that life cannot be bought, owned, sold, discovered or patented, even in its smallest forms.”

PAHO. In April 1995 the Pan-American Health organization passed a resolution opposing the HGDP, and stated:

“This type of research will have a negative impact on future health programmes and projects in indigenous communities, by undermining indigenous peoples' trust in the medical and health professions.”

The Pacific Consultation. The Pacific Consultation on the Protection and Conservation of Indigenous Peoples Knowledge developed a Treaty declaring a Life-Forms Patent Free Pacific, with specific objections directed to the HGDP.

North American Indigenous Peoples' Summit. In August of 1997, several hundred Indigenous peoples representing many tribes and over 60 organizations met to discuss the impact of the new biotechnology on their homelands and their people. This meeting was called "the North American Indigenous Peoples' Summit on Biological Diversity and Biological Ethics" It established the "Heart of the People Declaration". The preamble "expresses our profound concern for the well being of our Mother Earth and the Indigenous circle of Life known as 'biological diversity'." The Declaration further states:

“We wish to add our voices to ongoing global discussions regarding the protection of biological diversity, the safeguarding of traditional knowledge and sustainable development practices, and the ethical use and treatment of all forms of life in harmony, respect and the spiritual interconnectedness of the natural world.”

Ukupseni Declaration. In November of 1997, Indigenous people representing 25 organizations from 15 countries met in Panama to discuss the HGDP and the issue of human genetic piracy. This meeting was one the first opportunities for Indigenous people from Latin America to meet with North American Indigenous people who were working on the HGDP issue. The Ukupseni Declaration on the Human Genome Diversity Project was established as a result of the two-day meeting. The Declaration condemns the HGDP:

“It calls for a moratorium on the collection of genetic samples from indigenous peoples, and demands the repatriation of genetic samples and data already obtained by unethical measures. It opposes the application of intellectual property law, and patents, to human genes. It calls upon scientists to denounce any research conducted in a manner that violates the protocols that protect the human rights of human subjects. Finally it calls upon allies to work with Indigenous Peoples to demand protection for the human and collective rights of Indigenous Peoples.”

The Indigenous Peoples Coalition on Biopiracy. The Indigenous Peoples Coalition on Biopiracy was established in 1998 to address the theft of Indigenous blood, hair, and skin sampling, and as a concerted response to the HGDP. Coalition participants worked on strategies to protect their communities from exploitation. Members disseminated information to the local grass-roots levels. They built alliances for sharing current information as well as for implementing collaborative action and support among the participating organizations and individuals. An extensive list of key points has been developed by this coalition, the direct quotation from the document is as follows:

“After careful review of HGDP and

other independent investigations on the genome of indigenous peoples:

**a.** We declare absolute opposition to the Human Genome Diversity Project, and demand the immediate suspension of any activities to collect genetic samples, cell lines, or genetic data from indigenous peoples, including our deceased ancestors.

**b.** We demand the fullest cooperation of any government agency or independent research institute in the return of all genetic materials, cell lines, and data they may have in their possession to the appropriate governing authorities of the tribal group.

**c.** We oppose any attempt to monopolize or commercialize the genetic samples, cell lines, or data derived from the cell lines of Indigenous peoples through the application of intellectual property law and patent systems.

**d.** We oppose the genetic engineering of Indigenous peoples' genes and cloning. This includes cloning Indigenous peoples' genes or gene fragments into bacterial, viral, mammalian cell lines, or other vectors. We demand the immediate suspension of activities that are currently using any Indigenous peoples' DNA, genes or fragments in any cloning experimentation.

**e.** We demand the international scientific community condemn any research that has been carried out contrary to recognized human values and moral principles, and that violates the international codes of ethics described in the Nuremberg code and the World Medical Association Declaration of Helsinki.

**f.** We reaffirm the governing entities of Indigenous tribal peoples/nations have the primary authority to deny access to, refuse to participate in, or to authorize any removal of genetic materials from our peoples or territories. The ethical principle of "individual informed

consent" is also applicable, and is secondary to tribal governmental consent.

**g.** We demand that scientific endeavors and resources be prioritized to support and improve social, economic and environmental conditions of Indigenous peoples in their environments, thereby directly improving health conditions and raising the overall quality of life.

**h.** We demand an immediate moratorium on collections and/or patenting of genetic materials from Indigenous persons and communities by any scientific project, health organization, governments, independent agencies, or individual researchers.

**i.** We demand that the US government and any governing agencies, to not participate, fund or provide any assistance to the HGDP, or any related research projects which seek to research the genome of indigenous peoples.

**j.** We denounce the integrity of the report by the Committee on Human Genome Diversity of the National Research Council which gives unethical endorsement to the Human Genome Diversity Project while acknowledging the "lack of a sharply defined proposal that it could evaluate".

As Indigenous peoples we have many unanswered questions regarding the new biotechnology industry, many of them centre around the issue of respect and some refer to the expropriation of the circle of life or biodiversity. In many of our communities these activities have been referred to as the final act of colonialism against Indigenous peoples. I have reported the concerns that Indigenous Peoples have not only about the HGDP but about the potential threat to sovereignty and well being that theft of biodiversity has on Indigenous communities in North America and globally.

