

The Human Genome Diversity Project: Implications for Indigenous Peoples

*We reported on the Human Genome Diversity Project in *Abya Yala's* Dec. 1994 issue. Indigenous opposition to the project has been growing since that time, and the project has yet to respond adequately to fundamental ethical problems such as those raised in this article.*

By Debra Harry

The Human Genome Diversity Project (HGD Project) proposes to collect blood and tissue samples from hundreds of different Indigenous groups worldwide for genetic study. On the assumption that these groups are headed for extinction, scientists are rushing to gather DNA samples before they disappear. Then, they say, at least the human genetic diversity will be preserved in gene banks as "immortalized cell lines." But why the tremendous interest in saving the genes of Indigenous people and not the people themselves? Who really stands to benefit from this endeavor? What are the dangers and long-term implications of biotechnology and genetic engineering? These are questions Indigenous people must ask themselves in order to protect their interests in the face of such a mysterious and well-funded effort.

Debra Harry is a Paiute Indian from Nevada, USA. She is researching issues related to IPR and the HGD Project.

Issues of Concern

HGD Project scientists claim to be searching for answers to questions about human evolution. However, Indigenous peoples already possess strong beliefs and knowledge regarding their creation and histories; furthermore, this is not a priority concern for Indigenous people. The HGD Project's assumptions that the origins and/or migrations of Indigenous populations will be "discovered" and scientifically "answered" is insulting to groups who already have strong cultural beliefs regarding their origins. What will be the impact of a scientific theory of evolution and migration that is antithetical to an Indigenous group's common beliefs? Will these new theories be used to challenge aboriginal territorial claims, or rights to land?

Medical Benefits?

The often repeated claim that medical applications will be developed to treat diseases suffered by Indigenous peoples is a complete misrepresentation of the Project, and serves to coerce the

participation of subjects based on the false hope for medical miracles. The Project's mandate is simply to collect, database, and maintain genetic samples and data, not to develop medical applications.

The HGD Project will make the genetic samples available to "the public." However, it is not clear who will have access to the data and actual genetic samples. It appears that the HGD Project will maintain an open-access policy. This means that once genetic materials are stored in gene banks, they will be available in perpetuity, with minimal control, to anyone requesting access. Scientists need only demonstrate the validity of their scientific research in order to gain access to the samples. Medical applications are in fact likely to result from the eventual research, manipulation, and commercialization of the genetic materials. But they will most likely come in the form of pharmaceuticals or expensive genetic therapy techniques. Possible benefits will go only to those who can

afford the high costs of such treatments.

The proposition that medical benefits will result from genetic sampling is further suspect since no aspect of the project will take into account the role that existing and historical socio-economic or environmental conditions play in the health of Indigenous communities.

If an Indigenous population were interested in researching a genetic question specific to their group, they would not need the HGD Project to do so. Genetic research technology and exper-

Since 1980...there has been a disturbing trend in US patent law that extends patent protection to life forms.

tise is widely available. The enticement of potential medical benefits is an empty promise which will be used to gain access to communities for the collection of samples.

Commercialization, Ownership and Intellectual Property Rights

The HGD Project raises inevitable questions regarding both ownership of the genetic samples themselves and who stands to profit from the commercialization of products derived from the samples. The Project puts Indigenous peoples' most fundamental property—their own genes—in the hands of anyone who wants to experiment with them. In doing so, the Project opens the door to widespread commercialization and potential misuse of the samples and data.

The Project will enable "bioprospectors" to stake legal claims on the natural genetic resource base of Indigenous peo-

ples. Some of those claims will strike it rich, in the form of profitable patents. As in the case of future medical applications, the direct benefits from the HGD gene banks will go to those who can afford to invest in research, manipulation and commercialization of the genetic data. Patent law will be the primary vehicle which enables scientists to secure exclusive rights to the genetic samples. Patent laws grant a limited property right to the patent holder and exclude others from using the patented item for a specific period of time, usually for a 17-year period.

Patenting Human Genes

Since 1980, when the US Supreme Court ruled that the creation of an oil-eating microbe is patentable, there has been a disturbing trend in US patent law that extends patent protection to life forms. Since then, the US Patent and Trademark Office (PTO) has granted patents for newly created micro-organisms, living animals, and for human tissues and genes, breaking the long-standing policy that animate life forms were not patentable. The National Institutes of Health, and others, have secured patent rights for fragmented gene sequences, many with unknown function and physical significance. This trend has enabled research institutions and corporations to secure patents for almost 5% of the entire human genome, and has spurred a rush for ownership of the remaining 95% of the human genome.

Does anyone have the right to own a life form or to commodify parts of the human body? While many debate the ethical and moral implications of patenting life forms, in 1993 US Secretary of Commerce Ron Brown filed a patent claim on the cell line of a 26-year-old Guayami woman from Panama. Her cell

line was of interest because some Guayami people carry a unique virus, and their antibodies may prove useful in AIDS and leukemia research. Fortunately, international protest and action by the Guayami General Congress and others led to the withdrawal of the patent claim by the US Secretary of Commerce in November 1993.

Patent claims have also been filed by the Secretary of Commerce for the cell lines of Indigenous people from the Solomon Islands. The Solomon Islands Government has demanded withdrawal of the patent applications and repatriation of the genetic samples, citing an invasion of sovereignty, lack of informed consent, and moral grounds as the reasons for protest. In early March, Secretary Ron Brown rejected these requests, stating that "there is no provision for considerations related to the source of the cells that may be the subject of a patent application." In other words, according to existing patent law, the source of a genetic sample is irrelevant.

Indigenous people must be aware that it may be extremely difficult or impossible to recover or repatriate samples of our blood, tissues, or body parts, once they are removed from our bodies and stored elsewhere. In 1984 John Moore filed a lawsuit claiming that his blood cells were misappropriated while he was undergoing treatment for leukemia at the University of California, Los Angeles Medical Center. During his treatment, Moore's doctor developed a cell line which proved valuable in fighting bacteria and cancer. The UCLA Board of Regents filed a patent claim on this cell line from which they developed commercially valuable antibacterial and cancer-fighting pharmaceuticals. Moore claimed that he was entitled to share in profits derived from commercial uses of

these cells and any other products resulting from research on any of his biological materials. In a significant 1990 California Supreme Court decision, the court established that "donors" do not have an IPR property right in the tissues removed from their body (6).

Sample Collection

The HGD Project will seek the consent of the individuals and populations to be sampled. Questions of what constitutes "informed consent" and how it will be secured remain to be answered. The HGD Project has secured a grant from the J.D. and C.T. MacArthur Foundation (despite the expressed opposition of Native leaders) in order to develop a model protocol for the collection of genetic samples from Indigenous groups.

The concept of "informed consent" raises many unanswered questions in the minds of Indigenous peoples, such as: Who is authorized to give consent? Should consent be required only by the individual being sampled, or also include the governing body of that particular Indigenous nation? Can consent be granted by government officials of the nation-state in which the Indigenous nation is located? How will permission be obtained for collection of samples from the dead, or for use of fetal and placental tissues as sources for genetic samples? How will the project be explained in the local language? Will the full scope of the project and the short- and long-term implications and potential uses of the samples be fully disclosed? Will donors be fully informed of the potential for profits that may be made from their genetic samples?

Other Potential for Misuse

With genetic engineering technology today, it is possible to manipulate the 'blue-

prints' of living organisms. Gene technology makes it possible to isolate, splice, insert, rearrange, recombine and mass-reproduce genes.

—Andrew Kimbrell, *The Human Body Shop*, 1994.

Though genetic engineering still seems like science fiction to many people, it is a reality. Through genetic engineering, scientists are capable of reprogramming the genetic codes of living things to meet societal or economic goals. Transgenic experiments can mix plant genome with that of animals, and human genome with that of plants or animals. The ethical and legal questions raised by genetic engineering technology are numerous and unanswered. Nonetheless, this area remains virtually unregulated. While the HGD Project itself does not plan to do genetic engineering, no safeguards exist to prevent others from doing so with the HGD genetic samples.

Genetic manipulation raises serious ethical and moral concerns for Indigenous peoples, for whom any violation of the natural order of life is abhorrently wrong. Scientists are genetically manipulating existing life forms, altering the course of natural evolution, and creating new life forms. Genes are living organisms which reproduce, migrate and mutate. The full implications of genetically altered life forms released into the environment cannot possibly be anticipated.

Recommendations

Indigenous organizations need to alert all Indigenous peoples to the work of the Human Genome Organization (the body governing the HGDP) in order to prevent the taking of their genetic materials by this project, or by free-lance scientists, and to assist groups in

reclaiming any genetic materials that have already been taken.

Indigenous people must engage in community education and discussion about the full scope of this project and the potential dangers of genetic manipulation before they decide whether to participate. It is imperative that our communities become fully aware of the Project's implications and begin documenting proposed or current sample

According to existing patent law, the source of a genetic sample is irrelevant.

collecting. We need to form an international Indigenous research group to determine the extent of existing international protections for human materials, and to develop additional policies which insure the protection of our intellectual, cultural and biological property rights.

Indigenous people must call for a world-wide moratorium on the collection, databasing, transformation, and commercialization of cell lines and genetic materials of Indigenous peoples until international standards and regulation are put into place which fully protect the environment and the interests of Indigenous peoples.

For More Information Contact:

Debra Harry, P. O. Box 72, Nixon, Nevada 89424, (702) 574-0309 email:

Debra_Harry@Together.org or dharry@igc.apc.org

Jeannette Armstrong, En'owkin Centre, 257 Brunswick Street, Penticton, BC V2A 1P2 (604) 493-7181

RAFI-Canada, (Rural Advancement Foundation International), Suite 504-71 Bank Street, Ottawa, Ontario K1P 5N2, (613) 567-6880