



RAFI COMMUNIQUE

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Patents, Indigenous Peoples, and Human Genetic Diversity

Issue: The Human Genome Diversity Project, an informal consortium of universities and scientists in North America and Europe, has launched a campaign to take blood, tissue and hair samples from hundreds of so-called "endangered" and unique human communities scattered over the globe. The Project is supported by the U.S. government's National Institute of Health, and linked to the multinational, multi-billion dollar initiative to map the human genetic structure known as HUGO--the Human Genome Organization.

Impact: The sampling of human genetic material for scientific research, as currently being discussed by the Human Genome Diversity Project, has serious implications for indigenous peoples. Products and processes extracted from the collected material could have enormous commercial value. The material itself may be patentable even without further research. Will profits be made from the genes of poor people whose physical survival is in question? Who will have access to stored genetic material, and where will these collections be located? What benefits, if any, will accrue to the indigenous peoples from whom DNA samples will be taken?

When: The Project's initial five-year effort to collect human DNA samples from a minimum of 400 indigenous communities will cost between (US) \$23 million and \$35 million. Some participating scientists have already begun collection work, but the full project will get underway in late 1993 or 1994.

Introduction

Earlier this year, RAFI received a copy of the draft proceedings of the second Human Genome Diversity Workshop held at Pennsylvania State University (State College, Pennsylvania, USA) October 29-31, 1992, along with a preliminary list of 722 human communities targeted for DNA sampling. Some participating scientists have already begun human DNA collection work along the biblical Nile, in northern Chile, and in parts of Southeast Asia. The Project's formal campaign, however, may not be launched until late 1993 or 1994.

This issue of RAFI Communique provides an analysis of the draft report and numerous concerns surrounding the Human Genome Diversity Project's plans to collect human DNA samples from indigenous communities around the world.

Human Genetic Erosion

It is a tragic fact that many indigenous groups are in danger of becoming extinct. Ninety of Brazil's 270 indigenous communities, for example, have met extinction since 1900. More than two-thirds of the remaining 180 communities have less than 1,000 surviving members.

The economic opportunity to collect--and the push to preserve--human genetic diversity has been fired by the development of new biotechnologies and the formation of HUGO. Medical science has long been aware that there is not just one human genetic map. Each ethnic community may have a slightly different genetic composition. Some of the differences and mutations could someday prove to be invaluable to medicine.

The Human Genome Diversity Project estimates that an initial five year sweep

of relatively accessible populations will cost between \$23 million and \$35 million and will allow sampling from 10,000-15,000 human specimens. At an average total cost of (US) \$2300 per sample, the project will spend more money gathering the blood of indigenous peoples than the per capita GNP of any of the world's poorest 110 countries.

White blood cells from each person will be preserved in vitro at the American Type Culture Collection in Rockville, Maryland (USA). The human tissue (scraped from the cheek) and hair root sampling will be used in shorter-term studies. The project's leaders, concerned that human blood can only survive 48 hours outside of storage, are planning their collections carefully. "*One person can bleed 50 people and get to the airport in one day,*" they calculate.

Among those targeted for DNA sampling are the Yukaghir of Siberia (about 100 people remaining in the group), the Dorasque of Panama (50 remaining), the Amazon's Akuriyo (50 survivors), Asian communities such as the Salsiat of Taiwan, Somalis in the famine-laden Horn of Africa, and the Deleware and Sarcee of North America (each numbering around 600). Although the list is incomplete, the current roster stands at about 722 indigenous communities more or less equally divided between the continents:

Indigenous Communities
Targeted for DNA Collection

Africa	165
Asia	212
South America	114
Oceania	101
North America	107
Europe	23
 TOTAL:	 <u>722</u>

Project organizers stress that the list is incomplete and deficient in several areas including Southeast Asia and West Africa.

Control, Ownership and Access to Genetic Resources: Parallels between Plant Germplasm and Human Germplasm

Many of RAFI's concerns about collection of human genetic diversity stem from similar controversies related to the collection and storage of plant genetic diversity over the past two decades. Key issues relating to control, ownership and access to plant genetic resources include:

- the balance between in situ and ex situ plant germplasm collections;
- the location and ownership of ex situ (gene bank) collections;
- intellectual property rights over plant genetic resources.

The experience of Third World countries has been that scientists in industrialized countries have collected farmers' crop varieties for gene bank storage in the North. More than 90% of all the plant germplasm collected in the South in the last two decades has ended up in gene banks in Europe and North America. This material has been incorporated into Northern breeding programmes and has yielded billions of dollars of value to farmers and agribusiness in the industrialized world.

With the passage of new intellectual property laws in the North, virtually all of the collected material is either directly or indirectly patentable. This is cause for considerable consternation among Third World governments and has ultimately led to the creation of the Commission on Plant Genetic Resources, an International Undertaking on Plant Genetic Resources, and the International Code of Conduct for Plant Germplasm Collecting and Transfer at the United Nations' Food and Agriculture Organization (FAO). Many of the provisions in the Convention on Biological Diversity adopted at the UN's "Earth Summit" last June also address (albeit imperfectly) issues related to control and ownership of genetic

resources, particularly with regard to indigenous people.

Preservation Versus Conservation

In the context of international efforts to collect and conserve plant genetic resources, the working assumption is that local communities have the right to maintain their own plant material and the world community has an obligation to help them conserve and develop these invaluable resources. There is no assumption that the material is destined for extinction. Conservation and use of genetic resources must be carried out as a process for "development" rather than a last ditch drive for "preservation."

In the draft report of the Human Genome Diversity Project, "preservation" is the dominant theme, and there is an assumption that many or most of the human populations are inevitably going to disappear. The project's emphasis on preservation and its insensitivity to indigenous peoples is best exhibited by the term they use to describe indigenous communities that have been targeted for human DNA sampling: "Isolates of Historic Interest" (IHIs).

Nevertheless, the project organizers are clearly sensitive to criticism and aware that their planned activities could cause some dismay among indigenous peoples. The draft report notes:

"...the establishment of permanent cell lines needs to be explained in terms that are understandable, but that do not mislead subjects in any population. English terms such as "immortalization" of cell lines can be badly misunderstood...Similarly, there is no fully acceptable way to refer to populations that are in danger of physical extinction or of disruption as integral genetic units (gene pools)...In this Report, we refer to such groups as "Isolates of Historic Interest" (IHIs), because they represent groups that should be sampled before they disappear as integral units so that their role in human history can be preserved."

The Project is also aware that indigenous communities have rights, that the discovery of HIV-positive groups requires some action on the Project's part, and that there is such an issue as Prior Informed Consent. *"The population itself must demonstrably be provided a full level of informed consent,"* the draft states, *"Religious or other cultural concerns must be protected."*

Intellectual Property Rights

The report makes no reference to intellectual property issues, ignoring the fact that products or processes derived from the collected cell lines could be patented in the United States. The patenting of plants and animals is already a controversial topic worldwide. The patenting of human genetic material is far more controversial--especially if a corporation or government holding a patent stands to earn royalties from products derived from the genes of poor people whose physical survival is in question.

In the United States, the patenting of human genetic material is well underway. Blood samples collected by the Human Genome Diversity Project will be stored at the American Type Culture Collection, outside of Washington, D.C. (USA). A database search conducted by RAFI reveals that, as of November, 1992, the American Type Culture Collection held 1,094 human cell line entries. More than one-third of these are identified as being the subject of patent applications.

It is important to note that financial backing for the Human Genome Project comes from the U.S. government's National Institute of Health (NIH). In 1991, the NIH applied for patents on more than 2,800 genes and DNA fragments found in the human brain. The patent applications, denied by the U.S. Patent Office in 1992, were particularly controversial because the NIH scientists filing for the patents had no idea what function the gene sequences played in the human body. Despite the rejection of its

patent claims, the NIH asserts that it will re-apply for patents on human gene sequences in the future.

The potential profit to be rendered from indigenous germplasm was brought home to pharmaceutical corporations earlier this year when Genetic Engineering News reported on the discovery that thirty citizens of Limone, an isolated Italian community, are carriers of a unique gene that codes against cardiovascular disease. Swedish and Swiss pharmaceutical companies, as well as the University of Milan, have since swarmed over the townspeople, taking blood and other samples, and applying for patents. Scientists have isolated the mutant gene and cloned the protein. If the gene can be turned into a marketable drug--and this remains a very big "if"-- the profits could be tremendous.

Will indigenous people have a share in such profits? Are the Human Genome Diversity Project managers aware of the need to bring some benefit to the people sampled?

Storage Location of Human DNA Samples

The draft summary report of the Human Genome Diversity Project discusses the need to provide laboratory facilities and training at national and regional levels in developing countries. They also stress the importance of basic health care for indigenous communities, conceding that it would be some time before indigenous peoples would find much value in genetic screening services. In closing, the Project commented:

"The study of the human genome, including elucidating its diversity, should not detract, in any way, from the need to address the health problems of the Third World, the bulk of which could be solved by the wide-scale application of knowledge already available; what is needed is the will to do so and the commitment of adequate resources."

However, the project members also expressed a need to impose some conditions to their aid: "A condition for

establishing such labs, however, would have to be that they cooperate on an open basis with investigators interested in their region." In other words, the Project and its donors will require full access to all samples and duplicate storage in industrialized countries. There is little doubt that, as currently envisaged, the major human "gene bank" would be located in the United States.

Foreign Aid Diversion

Despite the clearly stated intention of the Human Genome Diversity Project's draft report, it is almost inevitable that foreign aid funds designated for Third World countries will be diverted to this project. The U.S. Agency for International Development, for example, could well decide that the construction of facilities and training to support the Human Genome Diversity Project--should come from foreign aid budgets. There is danger of this happening because the scientific and commercial pressure to establish the Project exceeds the pressure of developing countries to set their own aid agendas with donors. Monies that might have been used to provide poor communities with access to clean water, vaccinations, or more immediately-useful public health programs, will be diverted to this Project unless a transparent and conscious effort is made to prevent this from happening.

Biological Warfare Risk

Finances permitting, the Human Genome Diversity Project proposes to leave a duplicate sample of the DNA of each indigenous community with their national government. Failing that, samples would be left with regional institutions. Given the fragility of blood samples coming from remote areas (living samples are only viable for 48 hrs. outside of storage), the Project must depend on support from laboratory facilities at the national or regional level. According to the draft report, money will also be set aside for local training on how to handle cryogenic human material (freezing and

storing of blood samples in liquid nitrogen for long-term preservation).

However, the draft report of the Human Genome Diversity Project makes no reference to the potential danger arising from the fact that knowledge of an indigenous communities' unique genetic make-up makes it theoretically possible for unscrupulous parties to devise cheap and targeted biological weapons effective against specific human communities. However distasteful or technologically remote this suggestion may appear, human rights violations against indigenous peoples, by their own governments and/or other governments within their region, is a major cause of their "physical extinction." Internationally, experimentation with biological warfare is by no means an isolated incident. In a world of rapidly changing technological possibilities, the potential of using human cell lines for biological warfare cannot be ignored.

Will the six indigenous communities in Iraq, destined for "immortality" in the capital of Baghdad, have any notion of how their cell lines (exposing their full DNA) could be used in biological warfare? What of the eight groups in Amazonian Brazil or the six populations in war-threatened Uzbekistan?

Most indigenous peoples--now seeking their own seat at the United Nations--would be no happier knowing that their DNA samples are in national or regional hands than in the hands of the U.S. government.

Next Steps?

RAFI has provided information and analysis of the Human Genome Diversity Project to the World Council of Indigenous Peoples, Survival International, and Third World Network, as well as to its regional partners: CLADES in Latin America, SEARICE in Asia, Seeds of Survival in Africa, GRAIN in Europe, and ACFOA in Australia. RAFI has also sent its report to many development and human rights agencies and to the Faith community. RAFI's

Executive Director, Pat Mooney, addressed a mid-April meeting of the Pan-American Health Organization (PAHO) with indigenous peoples. The issue will also be presented at the UN Human Rights Conference in Vienna in June, 1993.

These steps were taken only after RAFI wrote to the Human Genome Diversity Project, expressing grave concerns about the implications of their plans for indigenous peoples. In its letter of 6 April 1993, RAFI suggests the following measures:

1. The Human Genome Diversity Project should immediately halt any collection efforts and advise any parties it is in contact with to do likewise;
2. The Project should then convene a meeting with the World Council of Indigenous Peoples, Survival International and other major international and regional organizations of indigenous peoples, to discuss the best mechanisms for addressing these issues.
3. The minimal conclusion to be reached would be that organizations of indigenous peoples would participate fully in every aspect of the Project and would have the equivalent of veto power over any aspect of the Project.
4. Together with indigenous peoples organizations, the Human Genome Diversity Project should take the project to the United Nations' Conference on Human Rights scheduled for Vienna this June in order to have the issues fully discussed by the international community.
5. Depending on the outcome of the above activities, RAFI and other parties engaged in plant genetic resources conservation and development activities would be pleased to work with indigenous peoples and the Project in a joint effort to conserve and develop genetic diversity.

As of mid-May, the Project's organizers have not responded to RAFI's letter of 6 April. With only a month to go before the UN Human Rights Conference, RAFI has determined that it must make its research public.

SOURCES:

Boyce Rensberger, "Science: Molecular Anthropology Tracking the Parade of Mankind Via Clues in the Genetic Code." The Washington Post, February 22, 1993, Final Edition, p. A03.

Draft Proceedings of the Second Human Genome Diversity Workshop, October 29-31, 1991, Pennsylvania State University, State College, Pennsylvania, USA.

Leslie Roberts, "How to Sample the World's Genetic Diversity," Science, vol. 257, p. 1204(2), August 28, 1992.

Michael Waldholz and Hilary Stout, "Rights to Life: A New Debate Rages over the Patenting of Gene Discoveries--U.S. Claim to Broad Chunks of the Human Genome Draws Fire From Some--The Very Basis of Biotech," The Wall St. Journal, April 17, 1992.

Leslie Roberts, "Genetic Survey Gains Momentum (proposal to collect DNA samples from aboriginal populations)," Science, vol. 254, p. 517(1) October 25, 1991.

Susan Danheiser, "Low Levels of Mutant HDLs in Italian Town Appear to Ward Off Cardiovascular Disease," Genetic Engineering News, Vol. 13, No. 2, January 15, 1993, p. 1.

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