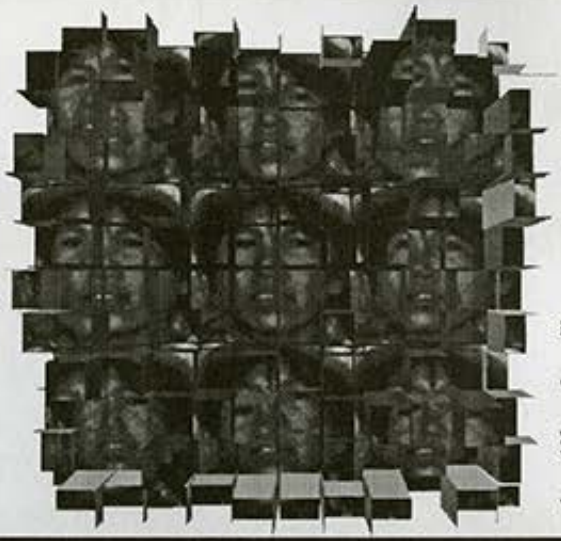

photo Alfonso Jaramillo

# Gene Genie and Science's Thirst for Information with Indigenous Blood

Daniela Spiwak

*"To take human DNA and patent its products, that violates the integrity of life itself, and our deepest sense of morality."*
*Isidro Acosta, President of the Guaymi General Congress.*

*"When a foreign government comes into a country, takes blood without explaining the real implications to local peoples, and then tries to patent and profit from the cell line, that's wrong."*
*Pat Mooney, RAFI Executive Director.*

If you haven't heard about scientific endeavors relating to the Human Genome, you soon will. As we plunge deeper into the decade, the bedfellows, biotechnology and science, are having a direct impact upon Indigenous communities with overriding repercussions for humanity at large. In the previous Abya Yala News journal, we provided a sketch of the Human Genome Diversity Project. Since then, much more information has been made available and patents applications on Native peoples' cell lines have been revealed. The following article hopes to elucidate the various components and implications associated with the Human Genome Diversity Project, highlighting its impacts on Indigenous Peoples around the world and course of action taken thus far.

While the potential benefits should not be underestimated, all of the related issues, from the method of execution to the exclusion of Native representatives in project discussions, are being seriously questioned by Indigenous organizations and support groups internationally. From financial compensation to the potential for biological warfare, it is essential that all foreseeable consequences and implications associated with the HGD Project be taken into account before further damage occurs.

Human Genome = 100,000 genes, containing an individual's hereditary information, found in all the cells of a human being.

Human Genome Organization- HUGO (based in London) Financial arm of Genome research: Walter Bodmer, President Charles Cantor, VP

Human Genome Diversity Project (HGD Project) - Proposal to collect and study genetic structure of various ethnic groups. A loose international consortium of universities and scientists that aim to gather blood, hair and mouth samples of targeted populations considered to be on the "verge" of extinction. Indigenous groups referred to as "Isolates of Historic Interest." Primary Project Initiator: Luigi Luca Cavali-Sforza, Professor Emeritus of Genetics at Stanford.

## BACKGROUND

Guided by the premise that the genetic composition of different ethnic groups may vary slightly, the project organizers aspire to gain a better understanding of why diseases vary so much in their geographic distribution and from there, try to find out if such variation is caused by human adaptation to local environments or changes in genetic make-up (5). Through these findings, it is hoped that new methods of dealing with fatal diseases, i.e. cancer, AIDS, etc. will be developed.

## METHOD

Through RAFI's research, it is known that 722 groups have been targeted for sample collection. The following outline provides a brief overview of the sampling and lab research process:

1.Collect blood, hair and mouth scrapings from selected population
2. Once gathered, samples rushed to lab (within 48 hours time) where white blood cells are to be "immortalized"
a)white blood cells are cultured in the lab then frozen in liquid nitrogen. Each cell contains a complete set of genetic DNA. This process allows the information in the genes to be preserved indefinitely for future study.
3. Once in this form, cells are turned into cell lines (continuously dividing cells that can provide a theoretically infinite supply of genetic material).
4. DNA to be deposited and stored in several "banks" around the world. The deposited material will be available for further research. Results from research can then be patented.

## CAUSE FOR CONCERN

The fact that Indigenous representatives and organizations have not been consulted or included in the planning process thus far, illustrates the paternalistic way in which the project is being conducted. Issues relating to patents, diversion of funds, access to gathered information and the potential threat of biological warfare have yet to be addressed satisfactorily by project organizers.

## I. OWNERSHIP AND PATENTS

It is a fact that some products and processes related to extracted material will have substantial commercial value. Once a patent on material extracted from a human cell line has been approved how will compensation be determined? What systems are in place for assuring that Indigenous peoples will be appropriately compensated on all commercial gains? To date, these questions have not been answered.

Human Genome Project- U.S. (There is also Medical Research Council (MRC). Human Genome Mapping Project in London) A $3 billion effort which began in 1988 with the goal of mapping each of the 100,000 genes found within chromosomes and sequencing the entire stretch of human DNA by the year 2005. Funded by the U.S. National Institute of Health (NIH) and the U.S. Department of Energy (DOE)

Players:
1. American Type Culture Collection, Rockville MD. Holding point for all types of collection; 60,000 rare materials from yeast to human cells and plant viruses (3). Legal deposit for living material by U.S. Patent and Trademarks office.
2. Private biotechnology companies
3. Various universities including: UCLA, UC Berkeley, Stanford, Yale

In terms of the General Agreement on Tariffs and Trade (GATT), the United States is doing everything it can to make patenting of all forms of life a legal part of the trade agreement. If passed as an international mandate, how will Indigenous people be able to hold governments, institutions, corporations accountable when such accountability will be regarded as a "barrier to free trade?"

## II. STORAGE FACILITIES A WORLD BANK OF 'DNA'

The idea is to create various "world banks" of DNA around the globe that would include both regional and national storage facilities and be accessible to government agencies, corporations, foundations, and interested researchers. In other words, the information will be made available to anyone who shows interest, including the institutions that have waged an unbridled war of oppression and genocide against Native peoples for the past 500 years.

## III. BIOLOGICAL WARFARE

In the context of genocide, marginalization, denial of traditional culture practices, who is to say a government, with a history of aggression toward Native populations and, in most of the cases, responsible for their physical demise, will not take the readily accessible information and use it to eradicate an "intransigent" group of people? There are sympathetic geneticists who feel that the feasibility of producing targeted ethnic biological warfare makes the possibility a long shot, but not out of the question. Where are the controls?

## IV. DIVERSION OF FUNDS

The exorbitant amount of money necessary to implement the project could be used to improve the present squalor that many of the targeted groups live in. In other words, the money could be spent on helping the groups that are facing "extinction" to overcome the various forces that have placed them in this critical predicament so that they can lead healthy, productive and self-directed lives now, rather than being recreated and "immortalized" in laboratories for future science projects.

## THE GUAYMI PATENT, A GLIMPSE OF THE FUTURE GONE AWRY WORST FEARS COME TRUE

Despite the efforts of HGD Project organizers to make it appear benign, equitable and absolutely necessary, the recent patent claim application on the cell line of a 26 year old Guayami woman from Panama, by U.S. Department of Commerce Secretary Ron

Brown, illustrates the underlying dangers and potential for the project to get out of control. Collected under dubious circumstances, the woman's cell line is being stored at the American Type Culture Collection(ATCC). Inquiries made by Isidro Acosta, President of the Guayami General Congress, and Pat Mooney, Executive Director of RAFI, about the cell line being repatriated to the Guaymi people, have been met with ambiguous responses and little action. Thus, the cell line remains in the hands of the United States government and the ATCC against the wishes of the original "owner."

On a broader level, if the U.S. government manages to make the patenting of human material legal under GATT, disputing a patent claim and repatriation would become that much more difficult. To make matters worse, there are reports of other possible patent claims on Navajo cell lines as well as prodigious cell line collection going on in Colombia. (6)

Along with the Guaymi community, Indigenous peoples and organizations as well as a growing number of concerned scientists are verbalizing their outrage. There have been various resolutions denouncing the HGD Project by First Nations. The Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples in June, 1993, stated the following:

Call for an immediate halt to the ongoing 'Human Genome Diversity Project' until its moral, ethical, socio-economic, physical and political implications have been thoroughly discussed, understood and approved by Indigenous peoples.

At the recent Second Continental Encounter of Indigenous Nations, Organizations and Peoples (CONIC), representing over 2,500 communities and organizations throughout the Abya Yala continent, issued a resolution denouncing genome research and the Guaymi patent claim. As information about the project reaches Native communities, opposition until Indigenous organizations are properly consulted, informed, and directly involved, has been the resounding response.

Cost and Funding:

I. HGD Project: Initial five-year effort is expected to cost between $23 and 35 million dollars. Expected to sample from 10,000 - 15,000 human specimens. Average total cost per sample ranges from $500 to as high as $2300 . (4) Currently seeking funding sources from government agencies and private foundations. funding will most likely come from the National Science Foundation. Hope is to obtain some of the money granted to the Human Genome Project.

II. Human Genome Project : Expected total cost $3 billion.10 times the grant money usually allotted for scientific research. Funding from the NIH and DOE.

## CONCLUSION AND CALL TO ACTION

At this point, the HGD Project has not received the substantial funding it requires to be carried out and therefore has the potential of being stopped. However, before breathing easier, it is important to take a look beyond the immediate situation. If the HGD Project does not materialize in its grandiose form, the possibility of genome research becoming diffused and anonymous makes monitoring even more difficult. The challenge, then, is to make sure that research of this nature stays transparent and accountable.

However grave the situation may seem, positive and effective action can be taken by individuals. International pressure demanding that all types of related genetic research be conducted with clear, structured and direct involvement of Indigenous organizations so that they are an integral part of the decision-making process, is vital. As the possibility for "a small number of corporations, universities, and governments owning life's genetic code,"(7) turns into reality, the time to mobilize is now!

## WHAT YOU CAN DO:

Find out who is doing research in your area and how it is being monitored. Urge that Indigenous organizations be consulted, informed, and involved during every phase of the project. For more information contact Professor Henry Greely, Head of the North American Ethics Committee at the following address:

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