Indians, Genes and Genetics: What Indians Should Know About the New Biotechnology ©1998

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Indians, Genes and Genetics:
What Indians Should Know About the New Biotechnology

By Debra Harry and
Frank C. Dukepoo

About the Authors

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Against Biopiracy

Forward

We Indians of the Americas are a very unique group of people who are widely known by our different cultures, customs and languages. Despite these differences, however, we share a common worldview. We are also a people of enormous endurance as history documents. We are a strong, yet gentle, people--perhaps too gentle.

Our early ancestors made significant contributions to the arts, architecture, astronomy, agriculture, mathematics, ecology, social science, political science and genetics, the results of which are evident throughout the world. How far we would have gone in these areas is unknown since our recent ancestors put them aside as they contended with colonialism.

By the turn of the century, "formal" colonization had ended. In ensuing years to the present, we struggled to recapture, retain and maintain what remained of our culture, identity and dignity. The struggle has not been easy. And, just as we were beginning to feel good about ourselves and what we recaptured, we are suddenly faced with a new battle.

In former times our ancestors fought their battles on land and in courtrooms. Their weapons were the bow and arrow and treaties...over 500 of them some say. Today the scene shifts as the battles in which we are engaged are being waged in scientific laboratories and patent offices. Our weapons are awareness, knowledge and choices. Call it "The Second Coming of Columbus," "The New Biotechnology," "The Bio-Revolution" or "Bio-Colonialism," it is here and will be with us for a long time. In a very broad sense, what we are talking about is "science." It is an area that we dare not ignore.

When we hear the word "science," most of us turn our backs or flee in fear thinking it is too hard or "not Indian." In like manner, when we hear the word "mathematics," we are literally petrified. Until recently, say the last ten years, very few of us were aware of the science of "genetics." Those few who pursued it as a career find it fascinating. Those who don't look on with fear because it's "too scary." We are not alone, however, as many Whites have the same fears about science, mathematics and genetics. Indeed, on many college campuses "genetics" is known as the "killer course."

In the academic arena it is widely accepted that the amount of general scientific knowledge doubles every ten years; biology every five years; and genetics every two. Whether this is true or not, many of us (including many Whites) sense that advancements in biotechnology and bio-medical science are moving at an incredible rate; perhaps too quickly. However astonishing, interesting, amazing or wonderful these advancements are, there are advantages and disadvantages as well as positive and negative aspects associated with them. It is like a giant two-edged sword. It cuts both ways meaning it can be extremely beneficial or detrimental to our existence.

"This is very interesting. But what does it have to do with Indian people or me as an Indian person?" you might ask. These are excellent questions and the answers can be found by examining our history.

In addition to losing of much of our land and coming dangerously close to annihilation, we served as "subjects" in thousands of research projects conducted by Western investigators who

Resources: Books, Publications, Reports and Web Sites

Biopiracy: The Plunder of Nature and Knowledge, Vandana Shiva, South End Press, Boston MA 1997 ISBN: 0-89608-555-4

Exploding the Gene Myth, Ruth Hubbard and Elijah Wald, Beacon Press, Boston MA 1993 ISBN: 0-8070-0419-7

The Great Human Diasporas: The History of Diversity and Evolution, Luigi Luca Cavalli-Sforza and Francesco Cavalli-Sforza, Addison-Wesley Publishing Company, 1995 ISBN: 0-201-40755-8

The Human Body Shop: The Engineering and Marketing of Life, Andrew Kimbrell, Harper-Collins Publishers, New York NY, 1994 ISBN: 0-06-250619-6

Human Genetics: Concepts and Applications, Ricki Lewis, Wm. C. Brown Publishers, 1997 ISBN: 0-697-24030-4

The Human Genome Project: Cracking the Code of Life, Thomas F. Lee, Plenum Publishing Corporation, New York NY, 1991, ISBN: 0-306-43965-4

Intellectual Property Rights for Indigenous Peoples: A Source Book, edited by Tom Greaves, Society for Applied Anthropology, Oklahoma City OK, 1994 ISBN: 0-9642023-0-1

Justice and the Human Genome Project, Timothy Murphy and Marc Lappe, University of California Press, Berkeley CA, 1994 ISBN: 0-520-08363-6

Perilous Knowledge: The Human Genome Project and Its Implications, Tom Wilkie, University of California Press, Berkeley CA, 1993 ISBN: 0-520-08553-1

Protecting What's Ours: Indigenous Peoples and Biodiversity, edited by David Rothschild, South and Meso American Indian Rights Center, Oakland CA, 1997 ISBN: 0-9635396-0-4

RAFI Communique, Rural Advancement Foundation International, PO Box 640, Pittsboro NC 27312 Office: (919) 542-1396 E-mail: communique@rafiusa.org Web Site: www.rafi.ca

GeneWatch, Council for Responsible Genetics, 5 Upland Road, Suite 3, Cambridge, MA 02140, Office: (617) 868-0870 Fax: (617) 491-5344 E-mail: crg@essential.org,

Evaluating Human Genetic Diversity, an evaluation of the scientific merits of the HGD Project by the Committee on Human Genome Diversity, Commission on Life Sciences released October 5, 1997. National Academy Press, 2101 Constitution Avenue, NW, Box 285, Washington DC 20418 Office: (800) 624-6242 Office (local) : (202) 334-3313 Web site: http://www.nap.edu

Cavelli Lab: http://lotka.stanford.edu/

HGD Project - Model Ethical Protocol: http://www-leland.stanford.edu/group/morrinst/protool.html

Human Genome Diversity Project, Morrison Institute for Population and Resource Studies, Stanford University, Stanford, California 94305-5020 Fax: (415) 725-8244 E-mail: morrison@forsythe.stanford.edu

Glossary

alleles Alternative of a gene for a particular characteristic.
amino acids The building blocks of protein.
autosomes Chromosomes other than the X and Y. Chromosomes which are not involved in determining the sex of an individual.
bases of nucleic acids Organic bases found universally in DNA and RNA.
base pair A pair of hydrogen-bonded nitrogenous bases that join the component strands of the DNA double helix. Adenine pairs with thymine, guanine pairs with cytosine.
biology The science that deals with the study of life.
cell The basic structural unit that makes up all living organisms.
cell membrane The outer boundary of a cell also known as the plasma membrane.
chromatin Areas or structures within a nucleus of a cell composed of DNA and proteins.
chromosome Histone protein and DNA structure found inside the nucleus of a cell that contain the cell's genetic information.
cytoplasm The more fluid portion of protoplasm that surrounds the nucleus.
deoxyribonucleic acid (DNA) A polymer of nucleotides that serves as genetic information. When combined with histone protein and tightly coiled, it is known as a chromosome.
diploid A cell that has two sets of chromosomes; one set from the father and one from the mother.
double helix The Watson-Crick model of DNA structure.
gamete A sex cell; a sperm or egg which contains half the genetic information of the parent.
gene A unit of inheritance that, in the classic sense, occupies a specific site (locus) within the chromosome.
genetics The science of heredity. The study of genes, how genes produce characteristics and how the characteristics are inherited.
genome The total genetic makeup of an individual or organism. A set of all the genes of an organism.
haploid A single set of chromosomes. Sperm and egg contain a haploid set of chromosomes.
heredity The familial phenomenon where biological traits are passed from parent to offspring.
Human Genome Project A 15-year, 3 billion dollar project conducted under the auspices of the National Institutes of Health to map and sequence all the DNA of a human prototype.
Human Genome Diversity Project A project designed to study human diversity and will involve a worldwide collection of genetic material from select indigenous people.
karyotype The chromosomal complement of a cell, individual or species often shown as a picture of chromosomes arranged in order from largest to smallest.
locus The spot or position on a chromosome where an allele is located.
nucleus The membrane-bounded structure found in a cell which contains the genetic material.
nuclear membrane The structure surrounding the nucleus that separates the nucleoplasm from the cytoplasm.
nucleoplasm The liquid matrix of the nucleus.
protein Macromolecules made up of amino acids.
protoplasm The living portion of a cell as opposed to the non-living cell wall.
X chromosome A sex chromosome. Two X chromosomes comprise a female.
Y chromosome A sex chromosome. An X and a Y chromosome comprise a male.
zygote The cell or entity resulting from the union of sperm and egg.

come from a vast range of disciplines. We strongly believe that not only will research continue on our people, it will increase in the near future, especially in the areas of genetics and biomedical research.

As Indian people we should be concerned and aware of any research that is conducted on our people or in our communities because there is the possibility that resulting data might be misinterpreted or used against us. The data might also be used to perpetuate or "prove" existing myths or stereotypes. We are particularly concerned about the Human Genome Diversity Project which we will discuss in the following pages. In addition to human research, we are also firmly convinced there will be an increase in plant or botanical research as pharmaceutical companies seek to "discover" and patent the medicinal properties of our native plants and knowledge of our elders and medicine people.

As an Indian person, you should be concerned since you might have an unusual genetic makeup, possess a rare gene or suffer from an "important" disease or medical condition thereby targeting you as a prime candidate in some future research project.

If you choose to participate, that is your personal decision. Before making that decision, however, we urge that you consider the following:

- ◊ Am I fully aware of the research I am getting into?
- ◊ Do I really understand what is going on?
- ◊ Am I aware of the short and long-term effects of such research?
- ◊ Have I weighed the positive as well as negative outcomes?
- ◊ Does this violate or go against my religion, my culture or my personal code of ethics?
- ◊ Do I really know what is in the "consent form"?
- ◊ Have I given my true consent?
- ◊ Do I know what will be done with my blood, tissue, hair or other samples?
- ◊ How will the research results affect me, my family, or my people?

These are extremely important questions. They are questions and issues that all of us must face as we enter the bio-revolution. The enormity of the issues prompted us to do this booklet. In doing so, we had one major objective in mind, which is to provide you information so that you can make informed and intelligent decisions about the research conducted on Indian people. In order to do this we have divided this booklet into two parts. In the first part we present the essential concepts and terminology of the science of genetics.

It is not our intent to give you a "short course" or even a "cram course" in genetics. Rather, is it meant as a "primer" to help you build a foundation and have a better understanding of this complex subject. This essential knowledge will enable you to comprehend the issues and make more informed decisions regarding yourself, your tribe or your community. In the second part we present an overview of previous and current human genomic and botanical research conducted in Indian commu-

nities in the Americas and in other indigenous peoples. It is important to become aware of the experience of others who have elected to participate. Learning from their experience will enable you to have a firmer grasp of the issues and the stakes involved. It will also provide valuable clues to what lies in the future.

Before we begin, we wish to emphasize that we do not intend to tell you what to do or make decisions for you be they pro or con. Our intent is to present the subject and the issues so that you can make intelligent, well-thought out and informed decisions about research in Indian communities. Your decisions are important because they will affect all of us.

In summary, it is important you realize that you have choices. You have options. Most of all, whatever you decide, we want you to feel comfortable about it. Your decision must be something you can live with.

Debra Harry and Frank C. Dukepoo

Essentials of Genetics

Introduction

Life is what living things do. Living organisms grow, maintain themselves, reproduce, respond to their environments, age and eventually die. Life is also complex, mysterious and sacred. No one knows exactly when, how or why life began. In humans and many other organisms, however, a new life begins with the union of gametes. At that miraculous moment of conception a new life begins when a single sperm of the father penetrates the egg of the mother. The sperm contains half of the "blueprint" of life for the offspring; the egg contains the other half. This "blueprint" is DNA or deoxyribonucleic acid. Biologists study various aspects of living things; geneticists study the "blueprint," how it is constructed, how it functions, how it expresses itself and how it differs from organism to organism.

Genetics Then and Now

Genetics is the study of the structure and function of genes and of the transmission of genes between generations. Modern genetics is said to have begun in 1900 with the "rediscovery" of Mendel by three independent researchers. Knowledge of genetic phenomena, on the other hand, has a history that is thousands of years old and probably began when humans first noticed similarities between parents and offspring or that certain traits or characteristics "run" in families. Ancient civilizations including the Chinese, Romans and Egyptians applied this knowledge which resulted in many domesticated animals. Indians developed many varieties of plants such as corn, potatoes, rice, beans, squash and other edibles. Present-day Indians still maintain different strains of different plants.

The "new genetics" has a rather short history but within the past two decades has achieved awesome and incredible progress. Its birth may attributable to Stanley N. Cohen and Herbert W. Boyer who, in the early 1970s, developed techniques for moving segments of DNA (genes) between organisms thus founding the genetic engineering revolution. Developments in this and related areas are simply astounding. Almost daily we read or hear about new developments or the discovery and identification of an important gene or the latest bio-medical breakthrough. In the reproductive area, technologies such as artificial insemination and in vitro (test tube) fertilization are

Indigenous peoples have expressed criticism of Western science which fails to consider the interrelatedness of holistic life systems, and which seeks to manipulate life forms using genetic technologies. There is grave concern regarding the short and long-term impacts of genetically-modified life forms on the environment.

Summary

The plus side of human genetic research is the promise of help for individuals with genetic diseases and progress toward combating or conquering illness such as cancer, diabetes and heart disease or learning more about our evolutionary history. Critics, however, note a serious possible misuse of genetic information. Corporations, for example, may someday demand genetic testing and refuse to hire individuals who carry certain genes or insurance companies may refuse or rasie the premiums on individuals with certain genetic backgrounds. There is even the spector of discrimination and racism.

The debate over these issues will go on because genetic research will continue. Mapping and sequencing will go on. We have arrived at a time when geneticists have profound knowledge and tools to manipulate the genetic material. The challenge we face is to ensure that the research will be conducted under the utmost ethical standards and that genetic information will be used wisely.

cell lines of an indigenous person from the Solomon Islands. The patent claim was also later abandoned. The US Patent and Trademarks Office (PTO) approved patents on the cells lines of a Hagahai man from Papua New Guinea. The patents were granted to the US Department of Health and Human Services and the National Institutes of Health (NIH) in March, 1994. Once again, the patent holders faced public outcry and in late 1996, the NIH abandoned the patent.

Gene Banking and Immortalized DNA

The blood samples will be 'immortalized" for future study utilizing a technique of cell transformation which keeps cells viable for several years, and capable of generating unlimited amounts of DNA available for research. The immortalized cell lines would be stored in various gene banks around the world. There is minimal control over who can have access to the genetic materials. The HGD Project collections of genetic samples will be available to anyone interested in doing research on them.

Euro-centric Scientific Theory and Discrimination

Expressing a sense of urgency, the HGD Project proposes to collect the DNA samples of indigenous peoples and store the collections in gene banks in order to "avoid the irreversible loss of precious genetic information". Referring to Indigenous populations as "isolates of historic interest (IHI's)" the HGD Project plans to immortalize the DNA of disappearing populations for future study. The initial conceptualization of the HGD Project has been widely criticized for its consideration of indigenous peoples as mere research subjects, with little regard for the continued livelihood of the targeted populations. The HGD Project has also be sharply criticized for failing to consult with indigenous peoples throughout its planning processes.

Scientists expect to reconstruct the history of the world's populations by studying genetic variation to determine patterns of human migration. In North America, this research will likely result in the validation of the Bering Strait theory. It's possible these new "scientific findings" concerning our origins can be used to challenge aboriginal rights to territory, resources and self-determination. Indeed, many governments have sanctioned the use of genomic archetypes to help resolve land conflicts and ancestral ownership claims among Tibetans and Chinese, Azeris and Armenians, and Serbs and Croats, as well as those in Poland, Russia, and the Ukraine who claim German citizenship on the grounds that they are ethnic Germans. The secular law in many nations including the United States has long recognized archetypal matching as legitimate techniques for establishing individual identity.

Conflicts with Common Indigenous Principles and Ethics

Collections of biological materials are taken not just from the living, but also from the deceased. For most Native peoples this represents a serious violation of the sanctity of our deceased ancestors. Many indigenous peoples regard their bodies, hair and blood as sacred elements, and consider scientific research on these materials a violation of their cultural and ethical mandates. Indigenous peoples also maintain a deep commitment to protect and maintain their ancestral identity. While there is no specific words for genes or DNA in our languages, an interpretation could mean genealogy, heredity, ancestry, or future generations. Many indigenous people consider any manipulation of their genetic composition a serious assault to their genetic integrity.

commonplace. While such technologies are not strictly genetic, they raise numerous ethical questions. Molecular biological techniques have found their way into the courtroom as the well-publicized trial of O. J. Simpson documents. Moreover, in 1997 the world was stunned by the news of "Dolly," the cloned sheep. And, in January of 1998, we learned that longevity might be extended by manipulating certain parts of the chromosome (end portions called telomeres) and that Richard Seed of Chicago was proposing to clone humans. Genetic research in the botanical world, though less spectacular, is important as scientists are attempting to unlock the secret medicinal properties of plants by studying the genetic material.

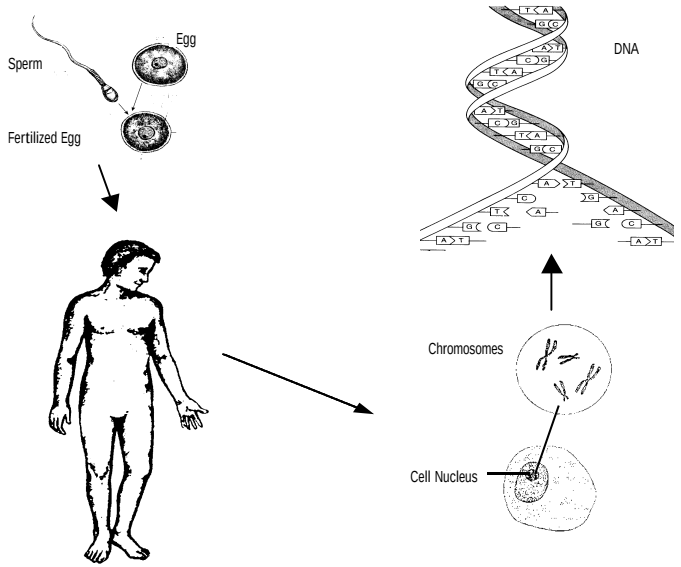
Nature of the Genetic Material

There is no question that genetics has had a profound impact on human affairs and will continue to do so in the future. But what are genes? Where are they located? How do they function? What is their role in the perpetuation of life? Figure 1 will help answer some of these questions.

After fertilization has occurred, a cell called a zygote is formed which contains the genetic material necessary for growth and development. The zygote divides rather rapidly and becomes an embryo, then a fetus, and eventually a baby is born. The adult human is composed of trillions of cells each of which, except red blood cells, contains the genetic material.

Figure 1.

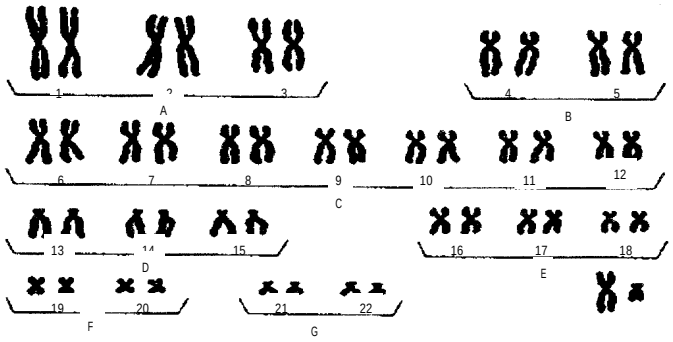
This picture illustrates where deoxyribose nucleic acid, or DNA, is found in humans. You inherit a set of chromosomes from your mother and from your father at conception. The chromosomes are located in the nuclei of cells in almost all tissues of humans. Nearly all cells contain chromosomes. The DNA is wrapped tightly around the chromosomes in a double helix, each strand connected by base pairs of Adenine and Thymine, and Guanine with Cytosine.



A typical cell has two major areas called the cytoplasm and nucleus. Within the cytoplasm are found organelles which keep the cell functioning. Within the cytoplasm is the membrane-bound nucleus which contains the genetic material. At certain times this material is diffuse, not easily seen and is known as chromatin. At other times the chromatin condenses into visible chromosomes. Embedded in the chromosomes are genes which occupy specific sites called loci. Chromosomes come in pairs as do their accompanying genes. Each cell contains 46 total chromosomes (23 from the mother and 23 from the father).

The total genetic material is known as the genome and is constant in species. Fruitflies, for example, have 8 chromosomes. Sometimes chromosomes are presented as a picture known as a karyotype. Figure 2, for example, is a karyotype of a normal male. Note that the chromosomes are arranged in order of size from the largest to smallest. The first 22 pairs are known as autosomes; the remaining X and Y are known as sex chromosomes. Females differ from males by possessing two X chromosomes.

Figure 2. Karyotype of Normal Male



Chromosomes are visible because they are tightly coiled. However, if we unwind a chromosome, we discover it is bound with histone proteins. If we continue to unwind, we find the complex and marvelous structure of the DNA molecule as postulated by James Watson and Francis Crick in 1953.

Chemically, DNA is composed of common elements including carbon, hydrogen, oxygen, nitrogen and phorphorus arranged as a double helix. The double helix is oftentimes described as a ladder where the outer supports are composed of deoxyribose sugar alternating with phosphorus. The connections between the supports are like rungs on a ladder and contain two types of paired bases. One pair is adenine and thymine (A and T); the other is guanine and cytosine (G and C). A gene might be visualized as a certain length of the ladder (which may be large or small) and may contain hundreds of paired bases which may be presentin any sequence.

At the molecular level, the DNA bases are read three at a time to specify amino acids which are the building blocks of proteins. Since proteins are large macromolecules that serve a structural

function (hair or nails) or as enzymes which are necessary for the chemical workings of the cell, DNA controls the phenotype (visible expression of a gene) by controlling protein synthesis. Different phenotypes reflect what is known as genetic variation.

Currently the Human Genome Project is attempting to sequence all the estimated 3 billion bases in humans to arrive at a prototype or "generic" sequence using mainly Northern European families. The Human Genome Diversity Project is proposing to investigate human variation and diversity by sequencing the DNA of select, and supposedly more "genetically pure," indigenous populations. Detecting genetic variation among indigenous populations becomes easier if there is a "generic" sequence for comparison which the Human Genome Project will provide. Hence, there is a great deal of interest in sampling Indian populations. But there are concerns as the next section discusses.

Implications of Genetic Research for Indigenous Peoples

Technological advances in molecular biology have enabled scientists to identify unique genetic data in human DNA. Since indigenous populations represent a significant percentage of the world's human diversity, they are also priority subjects for scientific curiosity. Worldwide efforts such as the Human Genome Project and its offshoot, the Human Genome Diversity Project (HGDP), as well as numerous independent research projects, are interested in collecting human DNA samples from Indigenous peoples.

Genetic research generally, and projects such as the HGD Project raise a complex range of legal, ethical and social issues which not only concern Indigenous peoples, but society at large. Many tribes are unprepared to critically evaluate proposals for genetic research involving their people. Policies are also lacking to protect the collective rights of indigenous peoples. Since indigenous knowledge systems and biological resources are extremely threatened by appropriation, tribes must prepare to protect their biological resources from exploitation. The following sections highlight some of the concerns regarding genetic research for indigenous peoples.

Commercialization and Ownership of Life

The HGD Project raises troubling questions regarding the definition of genetic samples or the products and data derived from them as "property." Patent law is the primary vehicle that enables scientists to secure exclusive rights to the commercial benefits of their genetic research. 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 17-20 year period. Patents are usually granted for newly created inventions, as a means of recognizing the scientist's "intellectual property rights." Once a valuable gene is located and isolated, it can be patented and mass-produced for commercial purposes. The HGD Project will maintain a policy of open access making genetic samples available to anyone seeking access, in perpetuity, opening the doorway for potential widespread commercialization and misuse of the genetic samples.

Three recent cases best exemplify the concern for patenting. The US Secretary of Commerce filed a patent claim on the cell line of 26-year Guaymi woman from Panama in 1993. A wave of international protest and action by the Guaymi General Congress lead to the withdrawal of the patent claim in late 1993. The Department of Commerce also filed patent claims on the human