

INDIGENOUS CONFLICTS

With nearly two-thirds of the population afflicted, the Nuu-chah-nulth Indians of Vancouver Island in British Columbia have one of the highest rates of arthritis in the world. Often passed down family lines, the genetics of arthritis in this unique population was studied extensively during the 1980s by Richard Ward, now head of the Institute of Biological Anthropology at the University of Oxford in England. As part of his study, Ward traveled through Nuu-chah-nulth territories in 1985 and collected 833 vials of blood from subjects who signed a consent form allowing him to screen the samples for arthritis biomarkers. Ultimately, Ward never was able to find the gene he was looking for. But he kept the blood samples and, unbeknownst to his donors, used them in genetic anthropology studies that identified the Nuu-chah-nulth as a distinct indigenous population dating back nearly 70,000 years.



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—JUDY GOBERT, Salish Kootenai College

Although he insists his actions were neither wrong nor unethical, the Nuuchah-nulth say Ward should have given the samples back once his arthritis studies were finished. That Ward shifted his research into areas not previously approved by the tribe, while also allowing other scientists access to the samples without the subjects' consent, has angered the tribe greatly. This incident, covered in the Canadian media in September 2000, is perhaps the best known example of a broader clash between genetic researchers and indigenous groups that is taking place throughout North America.

With the genomic era in full swing, scientists are interested in cataloging genetic variation among indigenous groups and studying their susceptibility to chronic diseases for several reasons. Indian populations are a convenient sample in terms of geographic area because they tend to be concentrated in areas such as reservations. American Indian populations are also very homogenous. Because there tends not to have been an influx of genes from other races and ethnic groups, scientists can study ancestral gene sequences in modern tribespeople. Finally, an enormous benefit for genetic research is that because the genes of American Indian tribes are so closely conserved, it allows researchers to more easily control for genetic variation and study other factors such as the role of environmental exposures.

However, blood and tissue samples from indigenous peoples are getting harder to come by. As in other countries, many U.S. tribes are suspicious of genomics and believe geneticists and the biotechnologies they spawn are out to exploit their genes and other sacred life-forms for commercial gain, usually to be enjoyed by people outside the tribe. Already wary of bioengineered transformations of sacred foods such as corn and fish, many American

Indians see human genomics as a science that challenges the spiritual basis of their existence.

Genetic researchers have also developed a reputation among Indian tribes as being culturally ignorant and arrogant. Some American Indians call such researchers "helicopter scientists" to describe how they fly into isolated communities claiming to be researching important health issues, and then, after collecting the necessary information and samples, fly back out, never to be heard from again. "They don't want to help us preserve the culture or language we evolved in," says Judy Gobert, dean of math and sciences at Salish Kootenai College on Montana's Flathead Indian Reservation. "They just want our DNA."

Specific Areas of Concern

In examining the opposition of American Indians to genomics, a number of broad themes begin to emerge. One item of concern is the indefinite storage of tissue samples for unknown future studies. Judith Greenberg, a scientist at the National Institute of General Medical Sciences in Bethesda, Maryland, is the project officer of the Human Genetic Cell Repository at the Coriell Institute for Medical Research in Camden, New Jersey. She acknowledges that the repository currently has no samples from indigenous peoples in its collection. She also says the repository "recognizes and respects that there is a great deal of concern and resistance among the tribes" to providing such samples.

Recently, the only such indigenous samples held at the repository were relinquished when the anonymous tribal donors demanded their return. Says Clifton Poodry, director of the Division of Minority Opportunities in Research at the National Institute of General Medical

Sciences, who is himself an American Indian from the Seneca Nation in western New York, "Native Americans will give informed consent to have their samples analyzed for a specific study. But they object to having those samples amplified and reproduced for future studies of which they have no knowledge."

According to Gobert, opposition to this practice is based partially on the spiritual attachment American Indians place on human tissue. "For me to even pluck a hair from my grandmother's head is abhorrent," she says. Because the samples are sacred, American Indians vehemently oppose their being used in ways that are inconsistent with tribal spiritual beliefs. Gene patenting, for example, is seen as a violation of nature throughout essentially all of the American Indian community. To ensure blood and tissue samples aren't used in ways that contribute to such practices, American Indians insist on retaining control over where the samples go and how they are studied.

The study of genomics is also worrisome to American Indians from several legal perspectives. For example, many American Indians believe genetic confirmation of the Bering Strait theory (which describes how early cultures migrated to North America by crossing the Bering land bridge) could be used to challenge aboriginal rights to territory, resources, and self-determination.

Also at issue, suggests Poodry, is whether genomic studies might ultimately be used to challenge blood quantum measurements, which define membership in a given tribe. Tribal membership is an increasingly controversial issue for many American Indians as more and more people seek to identify themselves with tribes, in part to share in the revenues generated by tribal casinos. This potentially destabilizing variable is something that American Indians would prefer not to deal with, Poodry says.

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—CLIFTON POODRY, National Institute of General Medical Sciences

Some tribes also worry that if genomic studies show that genes for diseases such as alcoholism are highly expressed among their populations, American Indians will be further stigmatized in the eyes of the public. “What we may attribute to genetics, the [laity] might simply label as race,” says William Freeman, director of research at the federal Indian Health Service in Rockville, Maryland. “This kind of information could be used to suggest that Native Americans are genetically inferior.” He adds, “We’ve heard these kinds of arguments many times before.”

Finally, there is a growing belief among some American Indians that high-priced genetic research is diverting funds that could be used to promote public health on the reservations. On 26 June 2000, the day that completion of a rough draft of the mapping of the human genome was announced, the Indigenous Peoples Council on Biocolonialism (IPCIB), an activist organization based in Wadsworth, Nevada, released a statement saying that “genetic research of this scale hurts, rather than benefits, indigenous peoples because it diverts public funds away from direct health care and prevention programs.” Gobert, who has close ties to the IPCIB, is emphatic in her view that genomics does nothing to improve the health of people afflicted with diabetes and other diseases common to indigenous populations. “We haven’t seen any benefits from genetic studies,” she says. “These diseases don’t have a genetic fix; they are lifestyle diseases. Genomics gives Native Americans false hope.”

However, Poodry and others admit to a level of exasperation with this view and suggest that it isn’t widely held throughout the Native American community. “This is an old argument,” says Poodry, “and it perpetuates a belief among Native Americans that genetic research is performed at the expense of public health. But genetic research and health care are independently funded, and one doesn’t necessarily take away from the other.”

A Growing Dialogue

One person bridging the divide between geneticists and American Indians is Francine Romero (who at press time was unable to complete procedures stipulated by her tribe to be quoted in this article). An epidemiologist with Oregon’s Northwest Portland Area Indian Health Board, Romero is perhaps the only scientist in the United States with a background in human genetics who is also an American Indian (she is from the Jemez Pueblo of New Mexico). Romero convened a meeting of tribal representatives, scientists, and agency officials in Rio Rancho, New Mexico, on 7–9 February 2001, hoping to initiate a dialogue that could form the basis of a national policy for engaging American Indians in genomic research.

The meeting was aptly timed: Just as scientists completed sequencing the human genome, a number of northwestern tribes, including the Confederated Salish and Kootenai Tribes of Montana, signed resolutions virtually banning gene research on their reservations. Meanwhile, the IPCIB is steadily promoting a message throughout Indian Country that genomics “has little regard for the life-forms it manipulates” and “contrasts sharply with an indigenous worldview,” according to *Indigenous Peoples, Genes and Genetics: What Indigenous Peoples Should Know About Biocolonialism*, a pamphlet posted on the group’s Web site. The IPCIB’s June 2000 statement further warns that genomics could result in “patents on the genetic inheritance of indigenous peoples and possible manipulations of their DNA, which violate the natural genetic integrity of their ancestry.”

Poodry says the views of the Salish and Kootenai and the IPCIB are at one end of a broad spectrum of perspectives on genomics among American Indians. “We have over 500 tribes in this country, and their perspectives on the issue differ greatly,” he says. “But

one thing they all share in common is a desire for respect.”

Future Resolution?

The dialogue begun by Romero and other stakeholders will continue throughout the year. Funding to study the ethical, legal, and social implications of the Human Genome Project, including American Indian concerns, is increasingly available through NIH grants. According to Poodry, the mission of the dialogue is to educate scientists and American Indians about their mutual desires and concerns. An important theme will be changes to informed consent procedures that ensure a level of donor control over samples as they make their way through the scientific community. Also important to the tribes, he adds, is that researchers look beyond the DNA and become aware of the cultures they are studying.

But Poodry recognizes that scientists often don’t have the time or the resources available for cultural meetings before research begins. For this reason, he says, funding organizations such as the NIH will need to develop a greater appreciation for cultural interactions between geneticists and American Indians. “Dr. Romero is leading an effort to develop a primer for funder organizations,” he says. “We hope they’ll take what we’re saying seriously.”

Ultimately, meetings between geneticists and American Indians may help to bridge the divides and lead to appreciation for study goals and objectives as well as respect for cultures and traditions. In the end, studying the pure and ancient blood of indigenous populations with cutting-edge genomic techniques may lead to something both sides of this issue value—a greater understanding of humans and their place in the environment.

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