SPECIAL ISSUE THE SCIENCE OF RACE

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RACE

WHAT IS IT GOOD FOR?

SCIENCE LOOKS AT FLESH AND BONES, GENES AND BEHAVIOR

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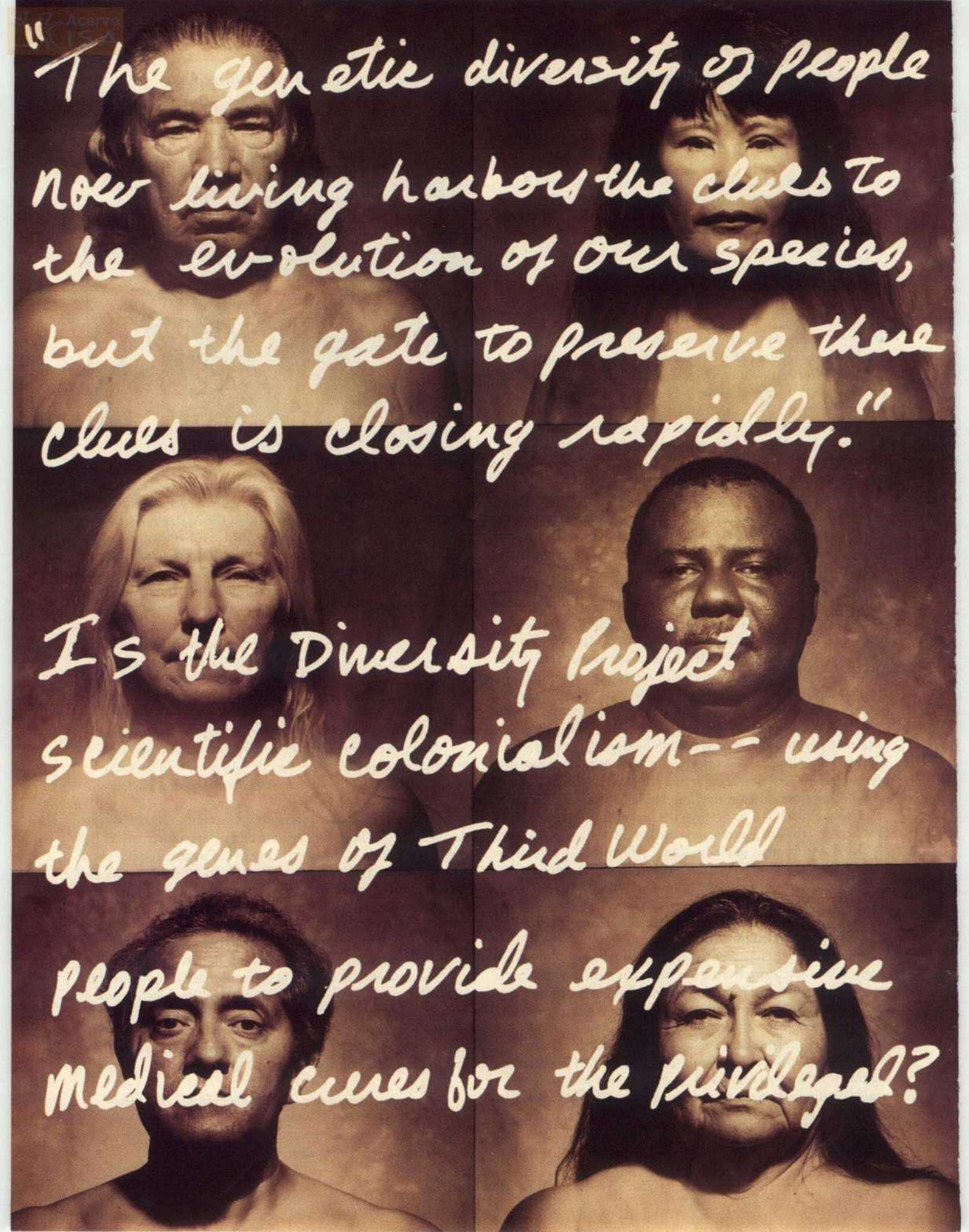

"The genetic diversity of people now living harbors the clues to the evolution of our species, but the gate to preserve these clues is closing rapidly."
Is the Diversity Project scientific colonialism -- using the genes of Third World people to provide expensive medical cures for the privileged?

end of the rainbow

THE LEADERS OF THE HUMAN GENOME DIVERSITY PROJECT WANTED TO FIND A WAY TO CELEBRATE AND PRESERVE OUR GENETIC DIFFERENCES. NOW THEY'RE BEING CALLED RACISTS.

by joann c. gutin

photographs by todd gray

WHEN HENRY GREELY is perplexed or troubled, his body English tells you as clearly as his words: the Stanford law professor and bioethicist leans back in his chair, stares into the middle distance, and slowly, absently tousles his own hair.

In his modest office this morning he's discussing the challenges of his two-year stint as one of the bioethicists on the organizing committee of the North American arm of the Human Genome Diversity Project. ("Has it only been since '92?" he wonders aloud. "It feels longer.") After two and a half hours spent grappling with variations on a single theme—"Why are some people so mad about the Human Genome Diversity Project?"—Greely's hair is decidedly the worse for wear.

That it should upset people seems curious. On paper, which is really the only place it exists so far, the project appears to be a singularly uncontroversial idea. It is merely a call for a coordinated effort by scientists on every continent to record the dwindling regional genetic diversity of *Homo sapiens* by taking DNA samples from several hundred distinct human populations and storing the samples in gene banks. Researchers could then examine the DNA for clues to the evolutionary histories of the populations and to their resistance or susceptibility to particular diseases.

Yet today the architects of the three-year-old program—a group of geneticists and anthropologists with irreproachable academic and political credentials—stand accused of being neocolonialists, gene pirates, and pawns in a conspiracy to develop race-specific biological weapons. The atmosphere surrounding the work is thick with suspicion: Greely recently heard one rumor about a medical researcher whose ongoing study in the Caribbean was abruptly shut down by charges that he would use his subjects' blood samples to clone a race of slaves. "Obviously *Jurassic Park* didn't help us," Greely says, managing a wan smile.

Clearly, though, reaction to the diversity project far exceeds mere blockbuster-induced paranoia about the perils of genetic engineering. University professors and indigenous peoples alike are voicing objections, and while the academic critique tends to be less vivid than what appears in the popular press, racism is the shared subtext. Is the Human Genome Diversity Project scientific colonialism, using the genes of Third World people to answer obscure academic questions or—worse—provide expensive medical cures for the privileged citizens of the developed world? Might it backfire and inadvertently supply more fodder for ethnic battles, as if any more fodder were needed? Or are its organizers merely victims of bad timing? Are the 1990s an impossible moment in human history to launch a project touching two of the rawest nerves in the culture: genes and race?

The Human Genome Diversity Project began innocently enough in 1991 with an impassioned open letter to the readers of the journal *Genomics* by a number of prominent researchers, among them the geneticists Luigi Luca Cavalli-Sforza of Stanford and Mary-Claire King and Allan Wilson of the University of California at Berkeley. The genus *Homo*, argued the letter's authors, has reached a critical juncture: indigenous peoples are being absorbed into the larger gene pool at an escalating rate, and if the information contained in their DNA is not collected quickly, it may be lost to humankind forever. "The genetic diversity of people now living harbors the clues to the evolution

of our species," they wrote, "but the gate to preserve these clues is closing rapidly." They urged members of the Human Genome Organization—an international consortium of scientists who are interested in human genetics—to "grasp a vanishing opportunity to preserve a record of our genetic heritage."

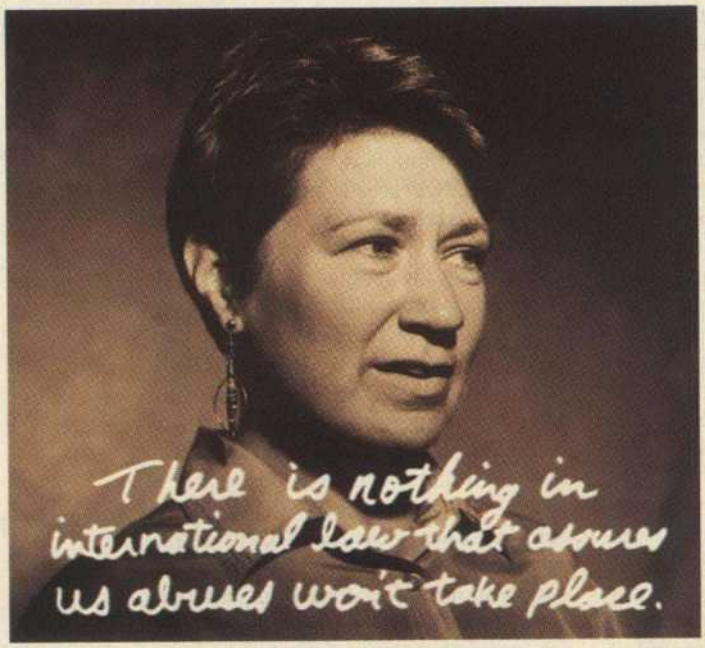
Their plea was heard not only by the nonprofit Human Genome Organization but by funding agencies that included the National Institutes of Health, the Department of Energy, and the National Science Foundation; all gave the letter's authors seed money, charging them with devising a way to collect a wider range of DNA.

Backers of the project saw it as a necessary adjunct to the much larger and better-funded Human Genome Project. The Human Genome Project often gets billed as the effort to map and sequence *the* set of human genes, but as Diversity Project organizers gently point out, that isn't quite accurate. Molecular anthropologist Ken Weiss, head of the North American Diversity Project committee, notes that the literal human genome is "the whole ball of wax," the sum of 5 billion people's DNA. What Human Genome Project researchers are actually analyzing is a sort of composite genome: 23 chromosome pairs donated by a mere handful of U.S. and European scientists. (As one wag observed, when they're finally mapped, those chromosomes will tell researchers everything there is to know "about one French farmer and a lady from Philadelphia.") And even *that* will take about 15 years and cost some $3 billion.

That's where the Human Genome Diversity Project would come in—it would supplement, particularize, and colorize the chromosome maps drawn by the Human Genome Project. As Weiss observes, "If we don't go ahead with this, then in ten years when the Human Genome Project is done, a Navajo, say, will look at those results and ask, 'Why did they bother? How well does that represent *me*?'"

From the outset, all the scientists involved called for sensitivity toward the sampled populations. These groups would include "historically vulnerable" people, warned the original *Genomics* letter, and using them merely as research subjects would inevitably lead to a "sense of exploitation and abandonment."

Yet the critiques began almost immediately. "The Human Genome Diversity ('Vampire') Project," reads a communiqué from the Central Australian Aboriginal Congress, "is legalized theft." "Your process," says a letter to the National Science Foundation from Chief Leon Shenandoah of the Onondaga Council of Chiefs, "is unethical, invasive, and may even be criminal. It violates the group rights and human rights of . . . indigenous peoples around the world."



The project's friends are perplexed by the commotion, believing that aside from its giant scale, the work doesn't constitute anything fundamentally new. Researchers have been collecting biological materials from indigenous groups for years; the Diversity Project is merely a way to organize that collection. Far from being a high-tech threat, say its backers, the project will do a better job of safeguarding subjects' rights and will generate better science than the scattershot data collection that preceded it.

As the guidelines stand today, anthropologists and geneticists around the world will be asked to gather blood samples from the groups they routinely study; the groups will participate in the Human Genome Diversity Project only if they want to. In addition, all the researchers will adhere to strict and uniform standards of informed consent; the property rights of donor populations to their DNA will be protected; and the material will be stored in a gene library accessible to all qualified researchers rather than disappearing into a refrigerator in one scientist's lab. The establishment of cell lines that will survive for 20 to 25 years—an expensive process—will guarantee that scientists into the next century will be able to ask questions of the genes that no one has yet thought of.

Why is the project necessary? After all, all humans, no matter what their ancestry, share most of their DNA. As Mary-Claire King is fond of saying, "We are all different, yet we are all the same." Every human carries about 6 billion base pairs—the chemical rungs of the DNA ladder—in the nuclei of his or her cells. Our personal DNA code differs from that of a random stranger by two rungs for every thousand, or .2 percent of the whole. The differences are smaller between family members and larger between people whose ancestors are unlikely to have intermingled in recent history. Still, a random sample of people in any small group from any location in the world—from rural Sweden to the Ituri Forest to Tierra del Fuego—will turn up 85 percent of all the genetic variation our species contains.

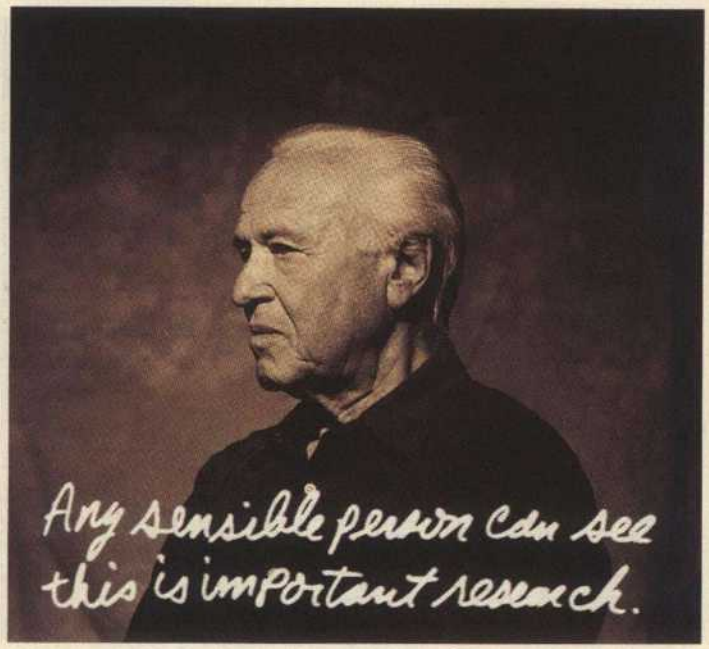
Nevertheless, the remaining 15 percent of human genetic variation isn't distributed randomly. It has a geographic pattern, which stems from past population movements and matings. Interestingly, the larger part of that 15 percent difference is not racial: almost 9 percent is reflected in differences among ethnic and linguistic groups within any given race. Only 6 percent represents genetic differences between races.

These kinds of patterns interest anthropologists and geneticists. The interest isn't merely historical: some of the variation finds expression in physical differences that intrigue medical researchers. The Navajo, for example, have very high rates of high blood pressure, some of which may be genetic in origin. Genetic research without Navajo samples

won't illuminate that problem. African Americans, as another example, experience high failure rates in organ transplants, partly because donors and recipients, even if both are of African origin, may have geographically different ancestries. If geneticists understood DNA variation on the African continent, tissue matching could be done more efficiently.

But—and this is the message that Diversity Project proponents repeat like a mantra—the patterns of variation that appear at the genetic level cut across visible racial divisions. Moving from the physical traits that scientists call phenotype—things like skin color and hair type—to the genetic level is like moving closer and closer to a pointillist painting. Twenty feet from Seurat's *La Grande Jatte*, for instance, you see Parisians and their dogs, but at two feet the image dissolves into dabs of pigment that might belong to a Parisian, a dog, or a tree. It's the same way with the human phenotype and the human genotype. "The closer in you go from what you see on the surface," notes Diversity Project planner Marc Feldman of Stanford, "the more unity there is."

This genetic unity means, for instance, that white Americans, though ostensibly far removed from black Americans in phenotype, can sometimes be better tissue matches for them than are *other* black Americans. "After the Diversity Project," predicts planning-committee member Georgia Dunston of Howard University, "we won't have the luxury of drawing distinctions between one another based on skin pigmentation anymore."



THAT DAY, however, may be a long time coming, judging from the initial criticism of the project. Perhaps what's most ironic about such criticism is that the scientists most involved in the project have established track records in human rights. As Feldman observes, "All of us have worked throughout our lives in an antiracist framework. Our political credentials are in order."

Charter member and 1960s activist Mary-Claire King, for instance, was putting her genetic expertise on the political line long before the Diversity Project was proposed: in Argentina she used DNA analysis to help reunite the kidnapped children of "disappeared" political prisoners with their grandmothers. In El Salvador she's been helping UN workers identify the remains of the 794 villagers of El Mozote, who were massacred by the American-trained military in 1981.

Throughout the 1970s, three-year project veteran Feldman publicly took on Nobel Prize–winning physicist William Shockley, who argued that whites are intellectually superior to blacks, debating him at the podium and in the press; Feldman currently heads the Morrison Institute for Population and Resource Studies at Stanford, which trains scientists and government officials from the developing world in ecology, population biology, and demographics.

And then there's Luca Cavalli-Sforza. It's Cavalli-Sforza, professor emeritus of genetics at the Stanford medical school, who remains both the project's biggest booster and the biggest target for the flak it takes. "Any sensible person can see this is important research," he says with characteristic aplomb. "But I must tell you, I was completely unprepared for the negative reactions we have encountered."

Straight-backed, silver-haired, and courtly—he registers somewhere between Marcello Mastroianni and David Niven on the charm meter—Cavalli-Sforza comes by his confidence honestly. A member of the Royal Society and the National Academy of Sciences, a recipient of the Huxley Medal for Biology and the Order of Merit of the Italian Republic, the 72-year-old Cavalli-Sforza is widely regarded as one of the world's leading geneticists. Though he has worked in the United States for most of his adult life, he remains an Italian in everything from his citizenship to his accent to his style of dress, which by American scientific standards is extraordinarily debonair.

Cavalli-Sforza has spent his entire career decoding the genetic clues to our hidden past, and he recently summed up his life's work in a 1,032-page magnum opus called *The History and Geography of Human Genes*. In the preface, he and coauthors Paolo Menozzi and Alberto Piazza note that written history, linguistics, and archeology are flawed tools for reconstructing the history of human evolution: "Only genes . . . have the degree of permanence necessary," they say, for discussing *Homo sapiens'* 100,000 years of "fissions, fusions, and migrations of populations."

Yet if Cavalli-Sforza is a man entranced by genes and the evolutionary patterns they reveal, he is acutely aware of how genetic information can be willfully misused, particularly when mixed with notions of race. "I get hate mail from neo-Nazi groups all the time," he says, gesturing at the pile in his office that awaited him on his return from a six-month sabbatical in Italy.

Cavalli-Sforza considers visible racial traits mere physiological frosting, functional adaptations of an organism to its environment, but his correspondents don't agree. "To say that race doesn't exist is a lie. And only an idiot would believe it," reads one laboriously handwritten example, which attributes Cavalli-Sforza's intellectual stance to a degenerative mental disease. Others are nastier, even frightening; all are anonymous. He shrugs dismissively, immune after years of attacks. "People like this never sign their names."

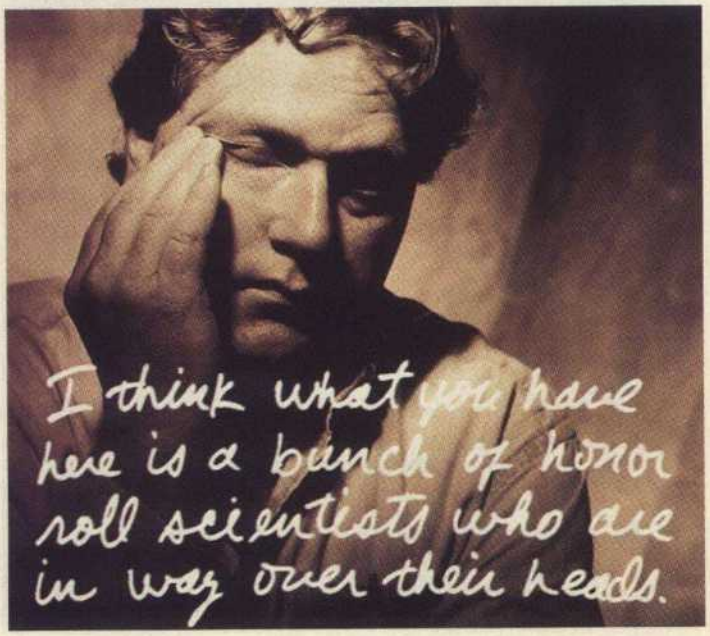
The criticism that's harder to shrug off, however, comes from more respectable quarters, including some mem-

bers of the scientific community, for "crimes" ranging from colonialism to outright racism. Some anthropologists suggest that Cavalli-Sforza got off on the wrong foot in 1991 by referring to African "tribes" but European "ethnic groups" before a large audience of anthropologists whose support for the project he was trying to enlist. "That's when he lost us," says one critic, who implies that the choice of words revealed a disturbing glimpse of a colonial mentality at the highest level of the project.

Ken Weiss heatedly rejects this interpretation. As for raising awareness of indigenous peoples, "I would say categorically that Luca has done more than anyone in the history of the species." He has his own explanation for the negative reaction to the project among some of his colleagues. "Many anthropologists," he contends, "are lamentably ignorant about genetics." And that ignorance breeds unwarranted suspicion, he thinks. "Laypeople sometimes have this idea that there's a black gene or a white gene, or a gene for criminal behavior. And there are a lot of anthropologists who don't know much more than that. If some anthropologists are worried that the project might be used for racist purposes, then maybe that's because deep down they really believe that there is a gene for race, and they are afraid to find it. But I'm not afraid of that, because I know a race gene doesn't exist. And that's what the project will show."

It seems clear that the high-profile Diversity Project has brought a long-simmering anthropological unease with genetics to a rolling boil. In particular, cultural anthropologists fear that the Human Genome Diversity Project gives intellectual legitimacy and—at a hoped-for $5 million a year for five years—a financial leg up to an approach they think shortchanges human complexity. Not surprisingly, they argue that it's more important to study and preserve the world's cultures than its genes. Greely, who has a long-standing amateur interest in anthropology, first became aware of this strain at a project-related meeting in Mount Kisco, New York, in 1993. "It was sort of like going out with somebody and being invited to Christmas dinner at her parents' house, with all of the family there," he recalls. "And suddenly they're reliving old arguments—what Uncle Joe said to so-and-so 20 years ago—and you don't have the foggiest idea what's going on. Fascinating, but I had the sense of being an outsider at a family fight."

Cavalli-Sforza attributes this family fight to a fundamental misunderstanding of how science itself works. "Some people say we should take a more *holistic* approach," he says, using quasi-audible italics to convey just how naive an idea this is. "What they don't see is that any science involves initial reductionism. You must simplify first, so you can get a handle on the problem." In an aside not calculated to win converts, he adds, "I don't think cultural anthropologists are scientists at all—more philosophers or social critics."



But cultural anthropologists are not the only ones taking serious issue with the Diversity Project. Biological anthropologist Jonathan Marks of Yale thinks its potential for answering evolutionary questions is being oversold. "You don't need molecular genetics to tell you that Danes are more closely related to Swedes than they are to Iroquois—just look at a map!" he says. "And it's not going to be able to tell you whether they're more closely related to Austrians than to Swiss, because at that level we're *all* mutts. This is 1990s genetics applied to questions anthropologists stopped asking in the 1940s."

Yet even the harshest scientific critics stop short of accusing project members of anything worse than naïveté ("a grand naïveté," Marks amends). "I think what you have here," says anthropologist Jason Clay, "is a bunch of honor roll scientists who are in way over their heads."

Clay, who founded and edited a journal focusing on the problems of indigenous peoples, supports the Diversity Project in theory. "You can't be afraid of information," he says. Yet as the head of Rights and Resources, an organization that brings together Third World agriculturists and "green" businesses like Ben & Jerry's and the Body Shop, he wonders about the details. Judging from his own experience with indigenous peoples, Clay says, well-intentioned explanations of why researchers want individuals' DNA will be useless. "Some of these groups don't know about germs, much less about genes or property rights," he explains. "What could 'informed consent' possibly mean to them?"

He also worries about the uses to which the samples might be put. In the past, botanicals taken from Third World countries have been used to develop new pharmaceuticals that are then sold back to their countries of origin at a profit. What if the Diversity Project were to uncover a gene that confers resistance to, say, an environmental toxin? "Indigenous peoples have been mined for their resources by big companies, and mined for their ideas by anthropologists," he says. "Now are they being mined for their molecules?"

Jon Marks concurs. "Just imagine how it seems to indigenes," he says. " 'We've taken your land, we've eradicated your lifeways, we've killed your people, but—guess what?—we're going to save your cells.' "

In response to these criticisms, Feldman simply sighs. "Look, if the Malaysian government is going to allow the Negrito population to be eliminated by selling their land to the Japanese timber companies," he replies wearily, "there's

not much the Genome Diversity Project can do about that. We're scientists, not politicians."

STILL, HOWEVER acrimonious it got, the debate about the Diversity Project was confined mostly to the laboratory, the seminar room, and the faculty lounge until 1993. That's when the Rural Advancement Foundation International got into the act. RAFI, an advocacy group concerned with issues of biodiversity and intellectual property, has for a decade been sounding the alarm over what it considers to be biopiracy: the theft of intellectual property rights of indigenous peoples. And it doesn't see the Diversity Project as an exception. "I think they're very naive with regard to the commercialization of cell lines," says Hope Shand, the research director of RAFI-USA. "If the cells are in repositories that are open to everyone, what's to prevent somebody from patenting them?"

According to RAFI's point of view, First World agribusiness has made a fortune from plant strains developed by Third World agriculturists, without funneling any of the profits back to the original owners. The fledgling Diversity Project, RAFI believes, could easily become a vehicle for similar abuses—not so much by project scientists as by outside researchers who might well be less scrupulous in their use of the sampled DNA. "There is nothing in international law," notes RAFI member Jean Christie, "that assures us those abuses won't take place."

RAFI workers have told indigenous leaders of their suspicions, buttonholed delegates at conventions, and E-mailed activist groups worldwide. Partly as a result of this lobbying, the European Green party, joined by the World Council of Indigenous Peoples and the Guaymi General Congress, has called for suspension of the Human Genome Diversity Project.

All this troubles Hank Greely very deeply; he sees the intellectual property issue as a misplaced concern. "There's no reason the project and RAFI should be enemies," he says. "There's no commercial money in the project, no pharmaceutical-industry backing. This is pure science." He concedes that the patent question is a knotty one but insists "we're happy to do what's right. It's just not clear, yet, exactly what's the best way to do that."

While the patent question may eventually yield to time, legislation, and good intentions, it may take more heroic measures to counter the darkest charge leveled against the project: genocide. "Unscrupulous parties," warns a RAFI newsletter, could "devise cheap and targeted biological weapons," effective against specific races, by using data collected by the researchers. The Diversity Project, in RAFI's view, makes the specter of genocide a biotechnological reality.

Georgia Dunston

This claim is the one that sends project scientists around the bend. "If people understood human genetics," snaps Feldman, "they'd know it can't be done."

"It's ludicrous," says University of Florida anthropologist and project committee member John Moore, "to suggest that we could be indifferent to the destruction of what most interests us."

"This is the most incredible rubbish, this DNA-poison idea," says Cavalli-Sforza. "It is part of a hate campaign waged against us."

But RAFI won't back down from its claims. "We're not scientists," says Christie, "but we've done research on biological warfare. People say our protests are naive, radical, or ill-conceived, but they're not."

Predictably, Hank Greely has a more measured response to even this dire accusation. "Governments *have* engaged in biological warfare," he says, recalling that in the nineteenth century the United States gave blankets impregnated with smallpox virus to Native Americans. "Indigenous people are right to be skeptical when people from the developed world come to them saying they want to help. It's a kind of survival trait—groups that didn't have it are probably gone now."

Greely doesn't for a moment think these fears are warranted vis-à-vis the Diversity Project, but in his view that's not the point. "If people are worried," he says, in what amounts to the ethicist's credo, "you have to deal with their fears, whether or not they have any basis."

It appears that his credo will guide the future progress of the Diversity Project. Feldman admits that they've made some mistakes—"You could call it arrogance," he says; "we sort of took it for granted that everyone would see this was a great project"—but he's certain they're on the right track at last. The MacArthur Foundation has awarded the North American committee a grant to develop an ethics program, and project leaders will be holding informational meetings for groups whose cooperation is being sought—meetings to explain the project as well as to answer questions about it. Feldman describes the first few such meetings, held in the spring of 1994, as "frank and good." Jon Marks applauds the trend. "Look, I think the project is a great idea; you can never have enough scientific data. The collection just has to be done right. It has to be done respectfully."

And Cavalli-Sforza, father of the Diversity Project, is heartened by the progress he's been seeing. The Chinese have established a Diversity Project committee, he reports, and collection has started in the British Isles, where the people of Cornwall have begun giving DNA samples. "We are still working on the ethics here," he says, "but that's very important. There cannot be any misunderstanding. We need to be—is the word *fireproof?* No—*bulletproof.* We need to be bulletproof." D