

# Chicago-Kent Law Review

---

Volume 75  
Issue 1 *Symposium on Legal Disputes Over  
Body Tissue*

---

Article 6

December 1999

## Genetic Diversity and the Politics of Difference

Margaret Lock

Follow this and additional works at: <https://scholarship.kentlaw.iit.edu/cklawreview>



Part of the [Law Commons](#)

---

### Recommended Citation

Margaret Lock, *Genetic Diversity and the Politics of Difference*, 75 Chi.-Kent L. Rev. 83 (1999).  
Available at: <https://scholarship.kentlaw.iit.edu/cklawreview/vol75/iss1/6>

This Article is brought to you for free and open access by Scholarly Commons @ IIT Chicago-Kent College of Law. It has been accepted for inclusion in Chicago-Kent Law Review by an authorized editor of Scholarly Commons @ IIT Chicago-Kent College of Law. For more information, please contact [jwenger@kentlaw.iit.edu](mailto:jwenger@kentlaw.iit.edu), [ebarney@kentlaw.iit.edu](mailto:ebarney@kentlaw.iit.edu).

# GENETIC DIVERSITY AND THE POLITICS OF DIFFERENCE

MARGARET LOCK\*

Advances in molecular genetics have, in theory, made it possible to systematically survey variation in the human genome across the entire human population. A group of human geneticists and molecular biologists proposed in 1991 to set such a project in motion; but, nine years later, this project remains in effect unfunded and unrealized. Given that we are bombarded daily by information in the media about advances in connection with human genetics, this blockage appears remarkable, particularly when one of the claims made by the involved scientists was that the project will “help to combat the widespread popular fear and ignorance of human genetics and will make a significant contribution to the elimination of racism.”<sup>1</sup>

In this paper, I will discuss the short, checkered history of the Human Genome Diversity Project (the “HGDP”), with emphasis on the worldwide criticism it has encountered from indigenous peoples—the proposed objects of its analysis—and, more recently, the scientific community. This criticism, often volatile, together with efforts at strategic accommodation with respect to the involved scientists’ proposed objectives and methods, provides an object lesson in the confrontational politics increasingly associated with many kinds of biomedical technology.

With the incremental procurement, commodification, and worldwide circulation of human DNA, tissue, and body parts, this new form of biopolitics is, I suggest, here to stay. As a result, scientific and ethical accountability will be more rigorously scrutinized. Participation in the production of research protocols by those on whom the research is to be conducted may well become the norm, and projects, protocols, methods, and plans for storage of data will be required to satisfy not only institutional review boards, but also those charged to represent the community on whom the research

\* Professor, Department of Social Studies of Medicine and Department of Anthropology, McGill University, Montreal. Funding for preparation of this article was granted by the Social Sciences and Humanities Research Council of Canada, grant number 410-99-0787.

1. HUMAN GENOME DIVERSITY COMM., HUMAN GENOME ORG., SUMMARY DOCUMENT 1 (1993) (on file with author).

is to be done. However, given that today privately funded companies are directly involved with a large proportion of government and university research, even with strict requirements for accountability in place, it is unlikely that fears about extensive body commodification, of primary concern to the public in connection with this type of research, will be dispelled.

### ACCOUNTING FOR HUMAN DIVERSITY

One difficulty for the proposed diversity project is that from the outset it has been upstaged by the multibillion Human Genome Project, an endeavor that has been primarily concerned with genetic sameness—not with genetic difference. It is only over the past two decades that we have become fully aware of how remarkably similar to one another human beings are in terms of genetics. On average, any two people will be identical for ninety-nine percent or more of their DNA. This close similarity suggests to the majority of biological anthropologists that we are descended somewhere between 150,000 and 200,000 years ago—very recently in evolutionary terms—from a common ancestor, or a small population of founders. It is this shared genetic heritage that the Human Genome Project is attempting to represent as it maps the human genome, an artifact that will become a standardized codification for human life. However, as Richard Lewontin warns, “[T]he’ human DNA sequence will be a mosaic of some hypothetical average person corresponding to no one.”<sup>2</sup> We will all become, in effect, deviations from this abstracted norm.

Despite the prodigious genetic similarities common to us all, substantial genetic diversity nevertheless exists between any two people (aside from identical twins) simply because of the number of genes (approximately 100,000, which frequently exist in more than one form) and the amount of DNA material involved. However, discussion about an evaluation of this genetic difference inevitably incites anxiety because, in the lived experience of so many people, assessment of biological difference, until now based almost exclusively on external morphological features, has been synonymous with discrimination and racism. It is entirely understandable that any proposed study of genetic diversity is a cause for serious concern. The thought of genetics now being drawn on with the idea of systematically validating biological difference among named groups

2. R.C. Lewontin, *The Dream of the Human Genome*, N.Y. REV., May 28, 1992, at 35, 35 (book review).

of people is a frightening prospect in light of its history of misuse and abuse for eugenic ends.

Before the advent of genetics, it was visible biological diversity together with language that captivated our imaginations when accounting for difference among groups of people. Aristotle, for example, posited eleven grades of development, including both inanimate and animate forms. The “strange races” that the explorers and soldiers of his time talked about were subsumed into this “Great Chain of Being” as subhuman categories.<sup>3</sup> Columbus, a product of classical European thought, expected to encounter humanoid monsters during his explorations; but ultimately, both the physical perfection and exotic difference of the peoples whom he encountered in the New World overwhelmed him.<sup>4</sup>

Until the sixteenth century, in those regions that came under the Judeo-Christian sphere of influence, the idea of race was closely associated with genealogical lineages. On Biblical authority, all lineages could be traced back to Adam and Eve; therefore, although physical difference was recognized, no *fundamental* division existed among human beings. However, around the seventeenth century in Europe, as a questioning of the dominant religious order escalated and a fascination with typology took hold, comprehensive taxonomies of the plant and animal worlds were created, among which those of the Swedish biologist Linnaeus are the best known. Differences among human races were included in certain taxonomies, and the idea of immutable difference, based on categories of inclusion and exclusion, began to be systematically explored. This was perhaps the first major step towards what was to become in the nineteenth century a thoroughly scientific study of fundamental human difference.

The French scientist Buffon is credited with introducing the concept of “race” into the biological literature in 1749, arguing from the outset that race was an arbitrary classification, serving only as a convenient label and not designating a definable scientific entity.<sup>5</sup> It has been suggested that the systematic application of the concept of race can be associated with the development of the capitalist economy and global expansion by entrepreneurs, particularly with the

3. See ARTHUR O. LOVEJOY, *THE GREAT CHAIN OF BEING* 55-59 (1936).

4. See I. Bernard Cohen, *What Columbus “Saw” in 1492*, 267 *SCI. AM.* 100, 102-06 (1992).

5. See Ashley Montagu, *The Concept of Race in Human Species in Light of Genetics*, in *THE CONCEPT OF RACE* 1, 3 (Ashley Montagu ed., 1964).

slave trade and the arrival of a substantial number of Europeans in North America, followed by the subjugation of the indigenous peoples.<sup>6</sup> It was not until after the abolition of the slave trade in America in the later part of the nineteenth century, however, when Darwinian theory of biological change supplemented Herbert Spencer's theory of social evolution that the way was opened up for race to harden into a scientific concept that became increasingly difficult to refute. As is well-known, this theory of social evolution incorporated the twin ideas of progress and hierarchy, in which the "European race" was judged as the most advanced.<sup>7</sup>

That the so-called races of mankind are able to "interbreed" has always presented a grave difficulty for those who would argue that distinct ideal types of humankind exist based on race. By definition, there can be no reproduction between species. Nevertheless, the best known of nineteenth century American biologists, Louis Agassiz, in order to sustain his racist leanings, argued that God had created blacks and whites as two separate "species,"<sup>8</sup> even though the evidence before his eyes obviously refuted such a conclusion. In America, the concept of race took deepest root, and classification based on racial categories is still made liberal use of in contemporary times in various professions and disciplines ranging from epidemiology, public health, and psychiatry to the law and forensic medicine.<sup>9</sup> That these classifications persist is politically significant because the majority of biologists, geneticists, and anthropologists, even though they assisted until the middle of this century in the legitimization of the race concept, have now abandoned this type of classification as scientifically invalid.

Biologists agree that geographic variation in gene frequency is almost all qualitative, or clinal—that is, discrete demarcations cannot be established on the basis of shared gene pools because they grade off into one another through space. Variation in blood types is a case in point. Mass migrations over hundreds of years have made

6. See generally LERONE BENNETT, JR., *BEFORE THE MAYFLOWER: A HISTORY OF THE NEGRO IN AMERICA* (Penguin Books rev. ed. 1966) (1962); Richard Cooper & Richard David, *The Biological Concept of Race and its Application to Public Health and Epidemiology*, 11 J. HEALTH POL. & L. 97, 99 (1986).

7. See AUDREY SMEDLEY, *RACE IN NORTH AMERICA: ORIGIN AND EVOLUTION OF A WORLDVIEW* 252 (1993).

8. See *id.* at 240.

9. See Margaret Lock, *The Concept of Race: An Ideological Construct*, 30 *TRANSCULTURAL PSYCHIATRIC RES. REV.* 203, 203-04 (1993); N.G. Osborne & M.D. Feit, *The Use of Race in Medical Research*, 267 *JAMA* 275, 275 (1992).

demarcation among biological populations even more problematic. Furthermore, human variation is primarily “discordant” rather than “concordant”—in other words, external similarities between groups of people are no indication that the majority of other biological features are common to both groups. To assign someone to a race based on skin color or specific anatomical features, attributes primary importance to those features, and forces all other variation to be ignored. Moreover, no discrete package of gene similarities has ever been described for any two of the so-called races, only *relative* frequencies of one trait or another. Nevertheless, biological diversity as expressed in external morphological features is so striking to us, so irrefutably “real,” that it has been the bedrock for naturalizing human difference for centuries. For over 100 years, anatomical and visible biological diversity has been capitalized upon to create the pseudoscientific discourse of race and the racism associated with it.

Although the concept of race has a comparatively short history, the political uses to which it is put today masks a much older system of distinction based on a fundamental principle common to humankind everywhere, namely that of descent. Race, claims Paredes, is more about genealogy than about genetics.<sup>10</sup> Categorization by race (or ethnicity for that matter) is one special case of lineage making in which culturally designated patterns of descent form structural principles for inclusion and exclusion that are used to regulate marriage and incest, residence rules, property rights, inheritance, access to political office, dispute settlements, and revenge.<sup>11</sup>

Prior to the discovery of genetics, it was often the idea of “blood”—its purity or mix—that provided the biological justification for lineage making.<sup>12</sup> Blood, language, religion, caste, and other forms of distinction constitute genealogies that in turn become the basis for economic exchange and solidarity among groups. As Levi-Strauss has famously shown, the circulation of women as part of marriage alliances created among men is very often central in

10. J. Anthony Paredes, *Race Is Not Something You Can See*, 38 ANTHROPOLOGY NEWSL. 1, 1 (1997).

11. For a review of concepts of race, see generally RICHARD H. THOMPSON, THEORIES OF ETHNICITY (1989). For an account of ethnicity and nationalism, see CLIFFORD GEERTZ, THE INTERPRETATION OF CULTURES 261-62 (1973); Charles Taylor, *The Politics of Recognition*, in MULTICULTURISM AND “THE POLITICS OF RECOGNITION” 25, 25-73 (1992); E.J. Hobsbawm, *Ethnicity and Nationalism in Europe Today*, ANTHROPOLOGY TODAY, Feb. 1992, at 3, 3. For a distinction between race and ethnicity, see Lock, *supra* note 9, at 216-18.

12. The idea of blood was not always exclusively used so.

producing economically powerful genealogies.<sup>13</sup> Blood lineages are important, therefore, primarily insofar as they legitimate, along with other forms of social distinction, fundamental aspects of reproduction, economic, and social exchange.

Of course, it was recognized empirically that certain types of disease and deformities tended to “run in families.” Such families with “bad blood” were, and often continue to be, discriminated against as liabilities to the community and society, or else as potentially polluting and therefore dangerous. During the course of this century, in those parts of the world infused with scientific knowledge, the symbolic power of blood has been largely subsumed by a discourse on genetics. Many of the newly discovered genetic diseases and disorders came early on to be associated with categories of race and ethnicity, which replaced an older discourse about lineage and genealogy. Despite the fact that we know from research on population genetics that “race is only skin deep,”<sup>14</sup> the use of race as a scientific category persists, and racism remains pervasive.

It was into this minefield that the Human Genome Diversity Project naively stepped: in the misplaced assumption that the “facts” of science would take the day, supposedly when it was finally understood by the public that we all, genetically speaking, share many more similarities than differences. From the start, the project had four major stumbling blocks. First, the science in which it was supposedly grounded was muddled and highly questionable—no natural “facts” would result from it. Second, claims were made that the research could bring results that would benefit the community in connection with health care; these claims were patently false. Third, the reductionistic approach of the project assumed that the “soft” social, linguistic, and political factors associated with descent patterns, genealogy making, ethnic affiliation, ideas about race, and racism are layered as a flotsam over the biological truth. This assumption was hotly disputed. The way in which science and pseudosciences both are socially produced passed unrecognized by the founders of the HGDP.<sup>15</sup> Further, the founders declined to address how aspects of

13. CLAUDE LEVI-STRAUSS, *STRUCTURAL ANTHROPOLOGY* 54, 60 (Claire Jacobson & Brooke Grundfest trans., 1963).

14. R.C. LEWONTIN ET AL., *NOT IN OUR GENES: BIOLOGY, IDEOLOGY, AND HUMAN NATURE* 127 (1984).

15. See Ian Hacking, *The Self-Vindication of the Laboratory Sciences*, in *SCIENCE AS PRACTICE AND CULTURE* 29, 29-64 (1992); John Law, *Introduction: Monsters, Machines and Sociotechnical Relations*, in *A SOCIOLOGY OF MONSTERS* 1, 1-19 (John Law ed., 1991).

science and pseudoscience are put to work in the reproduction of politics and society, considering this question as extraneous to scientific fact-making.<sup>16</sup> Fourth, no effort was made to actively involve those individuals and groups who were to provide DNA for the project in the project planning or execution of it other than as in their role as individual tissue donors.<sup>17</sup> In part as a result of this oversight, in addition to the criticisms of their scientific approach that the HGDP organizers encountered, they also faced from the outset massive resistance on the part of many of the indigenous peoples whose blood they planned to procure.

#### RESISTANCE ON THE PART OF THE OBJECTS OF INVESTIGATION

In his book *Marvelous Possessions*,<sup>18</sup> Stephen Greenblatt explores the way in which, at the time of the “discovery” of the Americas, new and “wonderful” knowledge about the natural world was garnered from native inhabitants by force or in exchange for cloth.<sup>19</sup> Greenblatt then explains that this knowledge was spirited away to be stored in European libraries and archives for posterity.<sup>20</sup> As his closing paragraph poignantly reminds readers, Greenblatt’s theme is not simply one of massive physical and intellectual exploitation.<sup>21</sup> In that paragraph, he describes a visit to the village church in Tlacoahuaya, in the valley of Oaxaca, where he discovered tucked away from view in a niche a stone carving of the Mixtec god of death gazing down from the ceiling into the face of the crucified Jesus, whose effigy was prominently displayed in the nave.<sup>22</sup> Greenblatt comments that “[t]he divinities have exchanged this sightless gaze, this perpetual circulation, for more than four hundred years”<sup>23</sup>—a memorial to the contradictory forces of resistance and assimilation at work when predatory outsiders mix with the “primitive” other.

Circulation of ideas and knowledge has accelerated geometrically

16. See MARGARET LOCK, ENCOUNTERS WITH AGING 370-87 (1993); ALLAN YOUNG, THE HARMONY OF ILLUSIONS 176-223 (1995); Margaret Lock, *Introduction to BIOMEDICINE EXAMINED* 3, 6 (Margaret Lock & Deborah Gordon eds., 1988).

17. The individual tissue donors may have received some form of compensation.

18. STEPHEN GREENBLATT, MARVELOUS POSSESSIONS (1991).

19. *Id.* at 86-118.

20. *Id.* at 6.

21. *Id.* at 150-51.

22. *Id.*

23. *Id.* at 151.



since the time of Cortes. Today, the technology of electronic communication sets up unlikely juxtapositions between “tradition” and “late modernity.” Native-L, an indigenous peoples news net, has been humming over the past few years with commentary and letters of protest relating to the proposed HGDP. On December 21, 1993, for example, Chief Leon Shenandoah and the Onondaga Council of Chiefs sent an e-mail communication to the National Science Foundation in Arlington, Virginia, demanding to know why the project had progressed to its fifth meeting (there had in fact been three official workshops by that time) “without discussion or consent of the indigenous nations and peoples it effects.”<sup>24</sup> The Chief and his Council found this situation “unconscionable” and in “violat[ion of] the canons of anthropology and science.”<sup>25</sup> This letter followed an account given a month earlier on the same network of the proposed \$23 million project, which will collect up to 15,000 human specimens, many from “isolates of historic interest.”<sup>26</sup> The key words in the e-mail communication had been taken directly from the language in the HGDP’s documents.<sup>27</sup> A concluding epithet completed the angry follow-up commentary disseminated by e-mail: “Didya ever notice how come there ain’t no Injuns on STAR TREK?”<sup>28</sup>

This skirmish is a fine example, I believe, of the way in which knowledge, which formerly might have remained contained within meeting rooms and in the publications and archives of government, academe, and industry, today becomes quickly available for public debate and politicization due largely to global access to sophisticated communication technology—the native gaze, hypersensitive to exploitation (and no wonder), glowers back. The sources of the human DNA—the objects of investigation—may have been conceptualized as specimens, as items from our uncivilized past in the minds of the planners of the HGDP (we would like to think that this was inadvertent), but as individuals they participate in politically

24. Letter from Chief Leon Shenandoah and the Onondaga Council of Chiefs to Johnathan Friedlaender, Division Director, The National Science Foundation (visited July 30, 1999) <<http://nativenet.uthscsa.edu/archive/nl/9312/0122.html>>.

25. *Id.*

26. Electronic letter from Dan Winter (visited July 30, 1999) <<http://nativenet.uthscsa.edu/archive/nl/9310/0123.html>> (reprinting and commenting on Robert L. Smith, *DNA Probe Angers the “Endangered,”* SYRACUSE POST STANDARD, Sept. 9, 1993).

27. Compare *id.*, with Leslie Roberts, *Anthropologists Climb (Gingerly) on Board*, 258 SCIENCE 1300, 1300-01 (1992) [hereinafter Roberts, *(Gingerly) on Board*], and Leslie Roberts, *How to Sample the World’s Genetic Diversity*, 257 SCIENCE 1204, 1204-05 (1992) [hereinafter Roberts, *Genetic Diversity*].

28. Electronic letter from Dan Winter, *supra* note 26.

astute communities, communities where inappropriate nostalgia about exotic others and unexamined racist notions on the part of outsiders about “pre-moderns” no longer pass undisputed.

The HGDP is a relatively small research project by today’s standards; nevertheless, even though it has been unable to obtain more than a tiny commitment to funding, it proceeds in an ad hoc way. The design of the project, as conceived in 1991 by two geneticists, Allan Wilson and Luca Cavalli-Sforza, is to gain new insights into the origins and evolution of humankind, human migration, reproductive patterns, adaptation to various ecological niches, and the global distribution and spread of disease.<sup>29</sup> The ultimate goal, pronounced at the first organizational meeting in 1992, is, quite simply, to find out “who we are as a species and how we came to be.”<sup>30</sup> The scale of this megaproject, its range through time and space, exhibits a remarkable hubris.

In order to undertake this ambitious task, the group printed a request in the journal *Genomics* asking for researchers worldwide to assist them in an ad hoc way by collecting DNA samples from hundreds of “indigenous” populations to create a database for the benefit of the scientific community.<sup>31</sup> At the first meeting, after extensive discussion, it was agreed that, for the project proper, DNA samples would be collected from between 400 and 500 populations, in addition to European populations (which would be handled separately).<sup>32</sup> The plan originally proposed to take, as a minimum, blood samples from twenty-five individuals in named populations, which would then be preserved as “immortalized” cell lines for future analysis (thus ensuring that there would be no further need to return for more blood at a later date).<sup>33</sup> The plan also originally proposed to collect as many extra blood samples as possible and take tissue scrapings from the inside of the cheek from each selected population.<sup>34</sup> It was suggested that hair root samples might also be collected.<sup>35</sup>

29. See Leslie Roberts, *A Genetic Survey of Vanishing Peoples*, 252 *SCIENCE* 1614, 1614-17 (1991).

30. Roberts, *Genetic Diversity*, *supra* note 27, at 1204 (quoting Mary-Claire King, one of the organizers of the meeting).

31. See L.L. Cavalli-Sforza et al., *Call for a Worldwide Survey of Human Genetic Diversity: A Vanishing Opportunity for the Human Genome Project*, 11 *GENOMICS* 490, 490-91 (1991).

32. See Roberts, *Genetic Diversity*, *supra* note 27, at 1204-05.

33. See *id.* at 1205.

34. See *id.* at 1204.

35. See *id.*

For the 722 groups of peoples who in 1992, without consultation, found themselves picked out from a preliminary selection of 7000 people to qualify as “genetic isolates,” loud alarm bells started to sound. Their blood would be converted into “cell lines” and stored in facilities, mostly in America, to which it appeared that anyone, for a small charge, could gain access for experimental purposes if they so desired.<sup>36</sup> Early HGDP publications indicated that highest priority was to be given to groups defined as unique, historically vital populations that are in danger of dying out or being assimilated.<sup>37</sup> It should come as no surprise, one would assume, that this kind of language would generate hostile responses, earning the endeavor the label of “vampire project.”<sup>38</sup> The geneticists who wrote the documents, however, appeared to be taken by surprise. Among some leaders of the groups who found themselves targeted, the idea was quickly established that, although their blood was going to be immortalized, they themselves were going to be allowed to continue on the road to extinction.<sup>39</sup>

In 1993, the Rural Advancement Foundation International (“RAFI”), which is the organization that first alerted the World Council of Indigenous Peoples about the proposed HGDP, urged HGDP organizers to convene a meeting together with indigenous peoples to address ethical and scientific issues associated with the project.<sup>40</sup> RAFI sought to ensure that from now on indigenous organizations would be involved at every stage of the planning and execution of the project and receive veto powers.<sup>41</sup> RAFI also recommended placing the project under United Nations control.<sup>42</sup> These suggestions, however, were not entertained for several years, even then only partially. Furthermore, at a conference held in Montréal in late 1996, one session of which was devoted to the HGDP, no indigenous peoples were invited to participate in the panel. This decision (possibly an oversight) resulted in a

36. See Jean Christie, *Whose Property, Whose Rights?*, 20 CULTURAL SURVIVAL Q. 34, 35 (1996); Darryl R. J. Macer, *Bioethics and Genetic Diversity from the Perspective of UNESCO and Non-Governmental Organizations*, in HUMAN DNA: LAW AND POLICY 265, 268 (Bartha Maria Knoppers ed., 1997).

37. See Roberts, *supra* note 29, at 1614-17.

38. See Jo Ann C. Gutin, *End of the Rainbow*, 15 DISCOVER 71, 72 (1994).

39. See Victoria Corpus & Alejandro Argumedo, *Indigenous Peoples' Reactions to the HGDP*, in THE LIFE INDUSTRY 145, 147 (Miges Baumann et al. eds., 1996).

40. See *Patents, Indigenous Peoples, and Human Genetic Diversity*, RAFI COMMUNIQUE (Rural Advancement Found. Int'l, Ottawa, Ont.), May 1993, at 1.

41. See *id.* at 5.

42. See *id.* at 13.

demonstration outside the meeting, followed by a refusal on the part of the police and hotel management to allow any of the demonstrators to enter the hotel. The demonstrators were not even permitted to pay the required fees to attend the conference and thus “exercise their democratic right to speak from the floor” as one conference organizer had suggested they should do.<sup>43</sup>

### CONSTRUCTING HUMAN BIOLOGICAL POPULATIONS

Not only is the question of inclusion of indigenous peoples in the planning of the HGDP at issue, but also its scientific merit. One of the most difficult problems associated with the HGDP has been the question of sample selection, an issue about which HGDP organizers disagreed among themselves.<sup>44</sup> In any given community, from whom and from how many people should DNA samples be taken? Above all, given that populations cannot be clearly demarcated genetically, what exactly should count as a human biological population in order to make a representative sampling? And how does one bracket one population off from another? Having done this, what exactly, if anything, does this information tell one about human migration over and above what is known from linguistic and archeological studies? Moreover, do scientists have a right to insist that this type of knowledge is more valuable and more “truthful” than that of local genealogies about the origins of specific peoples?

Several factors contribute to differences in human gene pools, one being the length of time of separation of populations under study, but it is imperative to establish a lack of subsequent genetic contact between these populations. Archeological and linguistic evidence indicates that subsequent contact has been the rule throughout prehistory and historical times, despite the creation at times of cultural barriers such as rules of endogamy. In addition to contact, recontact, colonization, abduction, and so on, there are the added problems of genetic response to local ecological conditions and culturally patterned behaviors of long standing. Further, so-called “genetic drift” takes place in those populations that have been geographically isolated for several hundred years or more and therefore reproduce almost exclusively within their own groups. These variables must all be taken into account when trying to

43. I was present at this event.

44. See Roberts, *Genetic Diversity*, *supra* note 27, at 1204-05.

establish what is to constitute a biological population. In short, reconstruction of a specific point in time at which one group becomes biologically distinct from another is not a realistic enterprise, nor is it scientifically verifiable, although certain of the HGDP planners originally assumed that this could be done.<sup>45</sup>

The conclusion of biological anthropologist Jonathan Marks is that it is unlikely that the genes of any one *socially* recognized group of people “are going to shed any light into anybody’s evolutionary history but their own.”<sup>46</sup> It has been argued, not altogether facetiously, that we would do better to sample the first fifty people we meet on the streets of New York if we wish to investigate overall genetic diversity.

A related problem arises because the HGDP, as first conceived, was designed so as to commit what in the social sciences is known as a “category fallacy,” namely the imposition of one set of data on another set of data of a different kind. Making a selection of contemporary groups identified on the basis of a shared culture, and assuming that their genetic constitution is also shared, is to conflate time and space inappropriately.

Further, analysis of gene pools tells one rather little about the history of relatively ephemeral socio-political groupings formed and disbanded throughout history. The San peoples of Southern Africa, for example, who are among the top of the so-called “genetic isolate list” and therefore a pristine example of an uncontaminated population by HGDP standards, contain three different language groups, suggesting relatively recent formation as a single group.<sup>47</sup> Wilmsen, the anthropologist, has shown that the San became isolated in the nineteenth century and that their isolation is related directly to colonialism.<sup>48</sup> Prior to that time, the San were fully integrated into complex local trading networks.<sup>49</sup>

The “Eta of Japan” also were placed on the HGDP list.<sup>50</sup> The

45. See Margaret Lock, *Decentering the Natural Body: Making Difference Matter*, 5 DIFFERENCES 267, 283-85 (1997).

46. Jonathan Marks, *We’re Going to Tell Those People Who They Really Are: Science and Relatedness*, in RELATIVE VALUES: NEW DIRECTIONS IN KINSHIP (S. Franklin & Susan McKinnon eds., forthcoming 2000).

47. See Roberts, (*Gingerly*) on Board, *supra* note 27, at 1301.

48. EDWIN N. WILMSEN, LAND FILLED WITH FLIES: A POLITICAL ECONOMY OF THE KALAHARI 127 (1989).

49. See *id.* at 78-129. See generally Sumit Guha, *Lower Strata, Older Races, and Aboriginal Peoples: Racial Anthropology and Mythical History Past and Present*, 57 J. ASIAN STUD. 423 (1988) (examining social classifications of indigenous tribes in India).

50. See Roberts, *supra* note 29, at 1614.

word *eta* is exceedingly pejorative and refers to an outcast group, primarily of leather workers who were set apart socially for several hundred years and have never been a distinct linguistic group. *Burakumin* (in more polite language) ceased to be legally recognized nearly half a century ago in Japan and clearly do not qualify as genetically distinct. Similarly, in North America, linguistic studies of founder populations show enormous movement and extensive contact between groups; there is no agreement as to how many separate migrations took place across the Bering Strait in prehistoric time. Yet, many of the Indian nations of North America were placed on the HGDP list on the assumption that they are genetically “pure.”<sup>51</sup>

The image of isolated, exotic cultures living close to nature, from which we moderns became separated as a result of migration and then evolved into a “higher” civilization, is one from an era shaped by Spencer’s theory of social evolution. We have all been very slow, anthropologists included, to recognize that the “people without history,” as Eric Wolf has ironically called “isolated” cultural groups,<sup>52</sup> are not frozen in time, artifacts from the past, in terms of culture or biology. When *Time* magazine reported on the HGDP, it quoted one project organizer as stating that “[a]ll Europeans are thought to be a hybrid population, with 65% Asian and 35% African genes.”<sup>53</sup> But “Africans” and “Asians” are not a dichotomous pair, homogenous opposites—this is folk anthropology, as are so many of the assumptions originally built into the HGDP. Fortunately, e-mail—refined bush telegraph—and other forms of timely responses have repeatedly forced the project organizers back to the drawing board.

The reconstruction of human evolution and prehistoric migrations is, I believe, a worthwhile endeavor, but contentious issues remain such as how to best go about the project and what exactly the contribution of molecular genetics to the project should be. It is misleading to suggest that, given the technology we have at present, one can indeed reconstruct *the* migratory history of a specific group of people. Project organizers, however, continue to indicate that they can do just this. Further, they claim that certain indigenous peoples in North America plan to cooperate so that the indigenous peoples may come to know their own past.<sup>54</sup> The contested politics of

51. See Roberts, *Genetic Diversity*, *supra* note 27, at 1204.

52. See generally ERIC R. WOLF, *EUROPE AND THE PEOPLE WITHOUT HISTORY* (1982).

53. Sribala Subramanian, *The Story in Our Genes*, *TIME*, Jan. 16, 1995, at 55, 55.

54. See John H. Moore, *Native Americans, Scientists, and the HGDP*, 20 *CULTURAL*

boundary making looms large here, and presentations at a recent conference in Montana at which I was present strongly indicated that local accounts of genealogies continue to be honored by many, perhaps the majority, of native peoples.

The following illustration reminds us just how politicized is the means by which certain individuals come to be included in a specific group while others are “disidentified,” and how the folk reconstruction of biological history can be made to do political work in creating rules for belonging and exclusion. Since the mid-1970s, the Mohawk of Kahnawake, who live very close to the island of Montréal, have sought self-government not by going to court, as has been the case for Indian bands in Canada for many years, but by unilaterally institutionalizing certain practices locally. The Mohawk currently conceive of themselves as a nation (they are by no means alone among indigenous peoples in doing this), and, in making this claim, they are seeking to regain control over establishing membership criteria for their community rather than abiding by those criteria enforced on them for several decades under the despised Canadian government’s Indian Act.<sup>55</sup> The majority of Mohawk reside in the province of Québec, which, as is well-known, has itself an ongoing battle with the Canadian federal government about boundary making. Thus, the Mohawk are reacting not only to both the historical and current political situation, but also in anticipation of what may happen in the future should the province of Québec gain its independence.

Historically, the Mohawk have taken an inclusive approach to membership—if one wanted to be counted as a Mohawk then that was sufficient; adoption into the community was commonplace. For the past twenty years, however, inclusive membership has been disputed. In its place, it was tentatively agreed that membership should be established in terms of “race.”<sup>56</sup> This move was made in part because militant “traditionalists” in Kahnawake wished to forcibly evict people described as “whites” from the community. The Band Council, whose police force was overwhelmed by the well-armed traditionalists (many of them Vietnam War veterans), called in

SURVIVAL Q. 60, 60 (1996).

55. Indian Act of 1876, 39 VICT., ch. 18 (Can.).

56. See Gerald R. Alfred, *Heeding the Voices of Our Ancestors: Kahnawake Mohawk Politics and the Rise of Native Nationalism in Canada* (1994) (unpublished Ph.D. dissertation, Cornell University) (on file with author).

the Québec provincial police to prevent the evictions.<sup>57</sup> Tension remained after this incident, and the Band Council felt obliged to develop a membership code and bylaws that would allow only “genuine” Mohawk to live in Kahnawake. The policy that they arrived at in 1981, after considerable consultation within the community, had three key elements: (1) all non-Mohawks were to be evicted from the community; (2) a moratorium was to be placed on mixed marriages between Mohawks and nonnatives—those who had mixed marriages were required to leave the reserve; and (3) a biological “measure” of belonging—the Mohawk Blood Quantum—was established in which an individual had to prove that he or she was at least fifty percent Mohawk to remain on the reserve.<sup>58</sup> For instance, if one grandparent was “clearly” not a Mohawk, then the individual ranked as seventy-five percent in the Blood Quantum.<sup>59</sup> An assumption was made that all generations who preceded those of the grandparents of the adults alive today were “pure” Mohawk if their names appeared in the reserve records.<sup>60</sup> The irony of the third part of this new policy was evident even to the Mohawk; the American government originally created the idea of a “blood quantum” to define the pedigree of slaves before the Civil War.<sup>61</sup>

The debate was inflamed because the Canadian federal government passed a bill into law to correct what was interpreted as a “sexist” element in the original Indian Act.<sup>62</sup> This bill requires that a former section of the policy be abolished: that an aboriginal woman, who is married to a non-aboriginal, and her children have no status as indigenous peoples; whereas an aboriginal man and his children keep indigenous status regardless of the status of the children’s mother.<sup>63</sup> The bill also required that women and children who had been denied status because of the Indian Act be accepted into the Mohawk community. This move, if followed through to completion, would mean that at least 1200 women and children must be assimilated into a community of 7000, a community that already suffers badly from underemployment (due in large part to documented racism and the

57. Band Councils are political units on Canadian Indian reservations equivalent to a municipal government. Because they are units that were originally imposed by the federal government, on any reservation there may well be active opposition to the Band Council.

58. See Alfred, *supra* note 56.

59. See *id.*

60. See *id.*

61. See Moore, *supra* note 54, at 62.

62. See Act to Amend the Indian Act, R.S.C., ch. I-5 (1985) (Can.).

63. See *id.* ch. I-5, § 4.



lingering effects of colonialism).<sup>64</sup>

Evictions of residents of Kahnawake have never actually been carried out, but for a number of years the blood quantum was taken reasonably seriously. People who contracted marriages with individuals outside the community were strongly encouraged to leave. However, from the start, many Mohawk described the new policy as racist and disliked the idea of policing their own community. Others argued that such a policy would be the only way to protect the Mohawk "culture," together with their relatively meager financial resources.<sup>65</sup> Any effort on the part of HGDP scientists to reconstruct Mohawk history by means of DNA analysis would obviously create further pain and havoc in this community. At the present time, Kahnawake residents agree that a blood quantum is inappropriate, and the policy has been dropped.<sup>66</sup>

The experience of the Yuchi, who reside in Oklahoma, and were the first indigenous peoples in North America to be directly contacted by a member of the HGDP about project participation, provides clear evidence of the contradictions evinced by this project. At the time they were approached by the scientists, the Yuchi had recently been denied their request made to the Bureau of Indian Affairs to be recognized as an independent political entity, a status that they hoped would assist them in the preservation of their culture and distinct language. When presenting his case, the HGDP representative explained to the Yuchi that they are a "unique" and distinct Indian tribe and thus their DNA should be preserved for posterity, an irony that was not lost on the Yuchi as they turned away the scientist in no uncertain terms.<sup>67</sup> Given the sensitive nature of land settlement claims and other political issues in connection with the status of the indigenous peoples of North America, fears are entirely justified of these drawn out disputes in Washington and Ottawa being thrown out should various culturally defined groups be found not to be genetically "pure." In a climate where genetic determinism is once again prominent, it would be a travesty of justice if political disputes were influenced by arguments based on biology. Instead, the political disputes should be influenced by arguments based on the history of

64. See Alfred, *supra* note 56.

65. See *id.* I am indebted to Regina Harrison, former Ph.D. student, Anthropology Department, McGill University, for this information.

66. See Alfred, *supra* note 56.

67. See Richard A. Grounds, *The Yuchi Community and the Human Genome Diversity Project*, 20 CULTURAL SURVIVAL Q. 64, 65 (1996).

the Americas of the past 500 years, and on the lived experiences of self-defined groups of people sharing a cultural and linguistic heritage, who are seeking restitution for past abuses and continuing discrimination.

### CAPITALIZING ON HYBRIDS

Although the HGDP insists that it has no working relationship with any drug companies, claiming that it is “resolutely non-commercial,”<sup>68</sup> the project, just by virtue of the fact that it is interested in genetic diversity, places itself in the middle of another exceedingly contentious issue. Major drug companies, in a search of unusual DNA sequences in human populations, send out regular forays into isolated regions to participate in what has come to be known as “gene prospecting.” The stakes are high because new vaccines and medications produced from unknown gene alleles can result in millions of dollars for the successful company. The greatest furor in connection with this “biopiracy” has to do with the patenting of DNA sequences, resulting, of course, in loss of all control of individuals over the uses to which their body materials are put and, in theory, their exclusion from any resultant profits.

Incidents such as an effort to patent DNA obtained from the blood of a Guaymi woman, which was later dropped after petitioning on the part of the Guaymi themselves, followed shortly thereafter by the patenting of a cell line containing an unusual virus found in the blood of a member of the Hagahai in New Guinea, have recently reverberated around the world causing consternation and resentment.<sup>69</sup> The Guaymi woman, it is claimed, gave “informed oral consent” (it is debatable what this means for an illiterate, unschooled individual). But in the case of the Hagahai, there was no documentation of either his “informed” consent or of permission being obtained from the Government of New Guinea to patent the cell line.<sup>70</sup> Patent number 5,397,696 for a Papua New Guinea human T-lymphotrophic virus has, it seems, turned out to have no commercial value, but it has been claimed that the anthropologist who mediated with the Hagahai had arranged ahead of time that fifty

68. Henry T. Greely, *Genes, Patents, and Indigenous Peoples*, 20 CULTURAL SURVIVAL Q. 54, 54 (1996).

69. See Christie, *supra* note 36, at 34-35.

70. See Michael P. Alpers, *Perspectives from Papua New Guinea*, 20 CULTURAL SURVIVAL Q. 32, 32 (1996).

percent of any royalties arising from a product or products made from the patented material should go back to the community.<sup>71</sup> Despite the unclear circumstances in which the blood was obtained, it was made known publicly that the Hagahai as a group were in full agreement with the project. However, patents taken out at the same time on cells obtained from Solomon Islanders were withdrawn after being challenged in court by a lawyer representing the interests of the Islanders.<sup>72</sup>

It has been noted repeatedly that bioscience owes much of its success with intervening into the human body to its conceptualization of the body as a mosaic of separable parts. One extension of this approach has been to understand body parts as detachable, as things-in-themselves, whether they are blood, organs, or human gametes that may be procured and then transformed into commodities.<sup>73</sup> In the case of human DNA, however, commodification is more complete than is possible with solid organs, which cannot be preserved for more than a few hours independent of the human body. Isolated segments of DNA can be preserved, in theory, indefinitely as “immortalized” cell lines. This technological processing of DNA means that cell lines are simultaneously naturally and culturally produced. Strathern has argued that it is this hybrid status that permits a claim to be made that DNA sequences can be owned through patenting because cell lines can be classed as inventions rather than as discoveries.<sup>74</sup>

One other point of interest in the production of DNA hybrids is that cell lines often contain, as in the Hagahai case, viral material in addition to the human protein. So, here is secreted yet another hybrid, one of self and a parasitic other, permitting Amar Bhat, a representative of the National Institutes of Health (the “NIH”), to assert in defense of the Hagahai and Solomon Island patent claims that “[the involved laboratory] cloned only the genes of the two viruses.”<sup>75</sup>

The “commodity candidacy” of body parts is culturally determined; but, at the same time, it is fluid and open to dispute both within and between cultures. With increasing globalization, the

71. See Teresa Riordan, *Patents*, N.Y. TIMES, Nov. 27, 1995, at C2.

72. See Amar Bhat, *The National Institutes of Health and the Papua New Guinea Cell Line*, 20 CULTURAL SURVIVAL Q. 29, 30 (1996).

73. See Rosi Braidotti, *Organs Without Bodies*, 1 DIFFERENCES 147, 152 (1989).

74. Marilyn Strathern, *Cutting the Network*, 2 J. ROYAL ANTHROPOLOGICAL INST. 517, 523-25 (1996).

75. Bhat, *supra* note 72, at 30.

circulation of body parts transcends local meanings and restrictions; production and consumption are often spatially at a great remove from each other, linked only by a string of intermediaries each with their own interests. When human blood, cells, and genetic material are understood simply as things-in-themselves to which monetary value can be attached, their worth as culturally significant entities, as the basis and affirmation of human life in a specific time and place, may be eclipsed.

No simple oppositions can be made between the knowledge and practices of the more than 5000 groups of peoples in the world recognized as indigenous and those of the so-called developed world. We live in an era of heterogeneity. Nevertheless, it is clear that concern about research into human genetic diversity is most apparent in those parts of the world formerly subject to colonization and decimation. Not surprisingly, the procurement and commodification of intellectual property, together with local plant and animal materials by agri-business, pharmaceutical companies, and other interested parties, have become common in these parts of the world in recent years. History is repeating itself on a scale previously unimaginable. Clearly, the time is long overdue when communities from whom procurement of knowledge and materials of all kinds are made should be able to exert control over what is done as well as benefit from it. This brings us to ethics.

#### ETHICS AND GENE PROSPECTING

In an effort to respond to its critics, the North American Regional Committee of the HGDP published a proposed *Model Ethical Protocol*, which was designed to place the American part of the project, at least, on an "ethical" footing.<sup>76</sup> One of the points made in the document is that, if any financial reward accrues from the specific analyses instigated by the HGDP, a mechanism should be in place whereby individuals or populations who donate blood can receive fair monetary compensation.<sup>77</sup> The protocol also states that express permission must be obtained from both involved communities and individuals before samples can be taken.<sup>78</sup> Community and

76. North Am. Regional Comm. of the Human Genome Diversity Project, *Model Protocol: Proposed Model Ethical Protocol for Collecting DNA Samples*, 33 Hous. L. Rev. 1431, 1436 (1997).

77. *See id.* at 1466-68.

78. *See id.* at 1442-47.

individual permission would also be required before applications could be made for patenting or the marketing of products.<sup>79</sup> In addition, the protocol recommended that a respected international body such as the United Nations Educational, Scientific, and Cultural Organization should be made use of as a trustee in connection with negotiations.<sup>80</sup> Finally, it was suggested that project participants should have the right to ask for their samples to be withdrawn and destroyed at a later date if they decided not to participate further in the project.<sup>81</sup> Despite the creation of this protocol, the collection of blood continues on an ad hoc basis, as has been the case for many years, with little or no consideration given to those from whom the blood is drawn.

While the welfare and interests of indigenous peoples have been noted as of importance to HGDP planners, no representatives of indigenous groups were consulted prior to 1997. It remains unclear as to what extent local governments will be involved in facilitating the project, and what recompense, if any, they would receive whether or not profit eventually accrues. It has been suggested in publications relating to the HGDP that assistance may be given with the training of local staff and in developing research centers to aid in the collection of blood.<sup>82</sup> This is described as an opportunity for indigenous peoples themselves to become actively involved in the project and to promote their own "development;" however, serious concern has been expressed by various communities that such initiatives may simply divert finances away from the implementation of urgently needed public health projects.<sup>83</sup>

It has also been asserted by HGDP planners that the project will be of benefit to communities in that it will provide information on the genetic patterning of disease susceptibility.<sup>84</sup> But the project design makes no provision for this because there are no plans to collect information about the local environment, phenotypic data, individual life histories, nutritional practices, or disease histories to match up with the tissue samples; all of this information is essential before disease susceptibility can be researched. There is a significant danger

79. *See id.* at 1466.

80. *See id.* at 1467.

81. *See id.* at 1468.

82. *See* Patricia Kahn, *Genetic Diversity Project Tries Again*, 266 *SCIENCE* 720, 722 (1994).

83. *The Human Genome Diversity Project*, in *THE LIFE INDUSTRY* 137, 139 (Miges Baumann et al. eds., 1996).

84. *See id.* at 138.

that participants would be easily misled into believing that cures for diseases such as diabetes are imminent if the project is successful, even though, in fact, research into therapeutics has never been among the HGDP's objectives. It was also suggested that health care would be administered to people at the time when blood is drawn.<sup>85</sup> This too is highly misleading because no responsible health care could be given without systematic follow-up and with little or no knowledge of local disease nosologies. Further confusion could arise because blood has often been given freely in the past by indigenous peoples when health care is the primary purpose. On occasion, the blood has then been sent at a later date to the NIH for genetic analysis without explicit permission, as appears to be the case with the Hagahai sample.<sup>86</sup> Therefore, the *Model Ethical Protocol*, while it raises the relatively innovative idea of the importance of both community and individual involvement in obtaining consent, does little in the way of providing reassurance that communities and individuals could benefit from the HGDP, or even place any trust in the protocol's stated objectives.

#### THE POLITICS OF HUMAN DIFFERENCE

In effect, the HGDP conceptualizes "exotic" bodies as a scarce resource, the essence of which can be extracted to transcend time and space and join the never-ending circulation of commodities integral to late modernity. The concerns of the individuals from whom the cells are taken (this activity continues regardless of the status of the HGDP) are primarily about a continued indifference on the part of the dominant world order to their condition; indigenous peoples remain marginalized by contemporary society and beyond the pale in the minds of many people living in the so-called developed countries. Aroha Te Pareake Mead, the Foreign Policy Convenor and Deputy Convenor of the Maori Congress in Aotearoa, has responded to this indifference with insightful barbs. She says that all human genetic research must be viewed in the context of colonial imperialistic history.<sup>87</sup> "Human genes are being treated by science in the same way that indigenous 'artifacts' were gathered by museums; collected, stored, immortalized, reproduced, engineered—all for the sake of

85. See Videotape: *The Gene Hunters* (Princeton University 1995).

86. See Yokotam Ibeji & Korowai Gane, *The Hagahai Patent Controversy: In Their Own Words*, 20 *CULTURAL SURVIVAL Q.* 33, 33 (1996).

87. Aroha Te Pareake Mead, *Genealogy, Sacredness, and the Commodities Market*, 20 *CULTURAL SURVIVAL Q.* 46, 46 (1996).

humanity and public education, or so we are asked to believe.”<sup>88</sup> Mead insists that a gene and combinations of genes are not the sole property of individuals: “They are part of the heritage of families, communities, clans, tribes, and entire indigenous nations.”<sup>89</sup> She adds that the survival of indigenous cultures will not come about through gene banks, but through an observance of fundamental human rights.<sup>90</sup> As far as Mead is concerned, patenting is not a tool of humanitarian research.<sup>91</sup> She claims, moreover, that talk of ethics is simply deception, arguing that informed consent among peoples such as the Hagahai, whose first contact with Caucasians was in 1984, was probably through sign language.<sup>92</sup> Mead insists that the burden of proof should be on the HGDP planners to demonstrate how their project will benefit indigenous communities.<sup>93</sup> She notes that the HGDP assumes that knowledge is “by nature” empowering to all, but her blunt response is that this is not so.<sup>94</sup> She adds that the issue for her is not one of “antiscience,” but rather one that most indigenous peoples of her acquaintance do not consider the HGDP to be “good” or “sustainable” science.<sup>95</sup>

In summing up some of the difficulties with the HGDP, Haraway, the historian of science, notes that the majority of indigenous peoples clearly do not consider themselves as a “biodiversity resource.”<sup>96</sup> The problems, Haraway insists, are “what may count as modern knowledge and who will count as producers of that knowledge.”<sup>97</sup>

### COLLEGIAL EVALUATION

In 1996, at the request of the National Science Foundation and the National Institutes of Health for the Research Council of the United States, a seventeen-person Committee on Human Genome Diversity was formed under the umbrella of the National Research

88. *Id.* at 46.

89. *Id.* at 48.

90. *Id.*

91. *Id.* at 51.

92. *Id.*

93. *Id.* at 49.

94. *Id.*

95. *Id.* at 50.

96. DONNA J. HARAWAY, *MODEST\_WITNESS@SECOND\_MILLENNIUM.FEMALEMAN@\_MEETS\_ONCOMOUSE™ 250* (1997).

97. *Id.* at 249.

Council.<sup>98</sup> The function of the committee was to “assess the scientific value, technical aspects, and organizational requirements of a systematic worldwide survey of human genetic variability and the ethical, legal, and social issues that would be raised by it before the commitment of substantial funds to any survey.”<sup>99</sup> The preface of their final report states:

In its fact-finding, it became apparent to the committee that the precise nature of the proposed survey was more elusive than the committee had envisioned; different participants in the formulation of its consensus document had quite different perceptions of the intent of the project and even of its organizational structure. . . . The committee found that there was no sharply defined proposal that it could evaluate; as a result, it chose to look at the issues posed by such a global survey of human genetic variation more broadly.<sup>100</sup>

The overall conclusion of the committee is that a global assessment of human genetic variability has substantial scientific merit and warrants support “largely because of the insight that the data collected could provide into the origin and evolution of the human species.”<sup>101</sup> The committee, nevertheless, foresees numerous ethical, legal, and human rights challenges in the prosecution of the project, challenges that cannot be overcome as easily as the technical, scientific, and organizational challenges that they also highlight.<sup>102</sup>

Prior to its four meetings and the final report, the committee let it be known that it would listen to presentations from those members of the scientific community and the public who wished to make statements. Information was disseminated on Native-L as well as other places. The committee paid attention to numerous written communications it received, and to the responses to a questionnaire circulated prior to the hearings.<sup>103</sup> The committee also listened to the fifty-seven people who appeared before them, including Luca Cavalli-Sforza, one of the two original proposers of the HGDP, anthropologist Clifford Geertz, and Maori leader Aroha Te Pareake Mead.<sup>104</sup>

The committee spent considerable time on the question of sampling issues and decided that, instead of a worldwide random

98. See COMMITTEE ON HUMAN GENOME DIVERSITY, NATIONAL RESEARCH COUNCIL, EVALUATING HUMAN GENETIC DIVERSITY at vii (1997).

99. *Id.* at vii.

100. *Id.* at vii-viii.

101. *Id.* at 2.

102. See *id.*

103. See *id.* at 11.

104. See *id.* at 11-12.



sampling of individuals, a population-based sampling strategy was most appropriate, where only basic group-identification data are gathered to ensure that the data cannot be associated with specific individuals. This method permits several hypotheses to be tested and avoids certain ethical complications, while not being exorbitantly expensive. Samples of several hundred persons or more would be taken from each population to ensure statistical validity. The boundaries of these populations can be determined on the basis of geographic location, self-reported ethnicity, primary language, sex, age, and parental birthplace (although this last set of data could inadvertently lead to the location of specific individuals and thus must be managed with caution). The example of the Mohawk indicates just how ethically difficult this type of data collection will be.<sup>105</sup> The committee was explicit that populations should include large, widely dispersed communities instead of small, isolated groups of people.<sup>106</sup> Accordingly, protocols for data collection will have to be designed for each group of people with their participation.

[I]t is crucial to have a complete research protocol for review before the actual consent form and process for obtaining consent can be designed and evaluated. For any specific goal-oriented protocol, it should be possible to anticipate the risks and benefits to the subjects and pursue informed consent accordingly. For projects that are not able to specify goals in sufficient detail to quantify risks and benefits reasonably, the worst-case scenario should be assumed: the benefits will be at the lowest anticipated level, and the risks at the highest. That means that the burden of proof for any DNA-sampling project that does not have a well-defined hypothesis will be high.<sup>107</sup>

The committee concluded that to always insist on both individual and group consent was perhaps extreme in that individuals might want to participate even when their communities refuse.<sup>108</sup> Where women have no rights to self-determination, the committee resolved that they should not be included in the sample.<sup>109</sup>

105. See *infra* pp. 96-98.

106. See COMMITTEE ON HUMAN GENOME DIVERSITY, *supra* note 98, at 35.

107. *Id.* at 59.

108. See *id.* at 63-64.

109. See *id.* at 63. This position ignores the large body of feminist and anthropological literature, particularly in connection with birth control, that reveals how, even in patriarchal society, women very often retain considerable control over their own bodies. See generally CONCEIVING THE NEW WORLD ORDER (Faye D. Ginsburg & Rayna Rapp eds., 1995); INTERNATIONAL REPROD. RIGHTS RESEARCH ACTION GROUP, NEGOTIATING REPRODUCTIVE RIGHTS: WOMEN'S PERSPECTIVES ACROSS COUNTRIES AND CULTURES (Rosalind P. Petchesky & Karen Judd eds., 1998); PRAGMATIC WOMEN AND BODY POLITICS (Margaret Lock & Patricia A. Kaufert eds., 1998). It also ensures that, should benefit finally

The report also pointed out that certain epidemiological findings with respect to human genetics might result from the HGDP if population sampling is used.<sup>110</sup> For example, it may be possible to determine some useful information about the global public health problem of noninsulin dependent diabetes, which is disproportionately present in indigenous populations. However, without information about specific individuals, their families, and their life histories, it will not be possible to do more than perhaps generate some hypotheses about susceptibility to diseases to which an individual's genotype makes a contribution.

In trying to make recommendations, the committee found itself frustrated by the absence of information on what repositories of DNA materials had actually been created and were, in theory, available to scientists for investigation.<sup>111</sup> It is evident that the longstanding concern of RAFI, that DNA material is being secreted away with the hope of profiting from its transformation into pharmaceutical material, is more than justified. As of 1995, there were 148 commercial or academic tissue depositories in the United States and seventy-five in Canada.<sup>112</sup> A survey of the Canadian facilities found that fewer than one-third of workers handling human tissue samples were aware of any institutional policies related to the management and distribution of samples.<sup>113</sup>

Despite these loopholes, the committee recommended that funding, once secured, should go initially to that part of the HGDP that would originate in the United States.<sup>114</sup> The committee reached this decision believing that the North American Committee of the HGDP had already grappled with many of the ethical issues and assuming that this experience should be used as a model for research designed in other parts of the world.<sup>115</sup> The committee also recommended that existing DNA repositories should be identified, but they did not spell out how they might be regulated.<sup>116</sup> Suggestions about storage, management, and patenting issues in connection with

accrue to individuals who participate in a study such as the HGDP, women will not be beneficiaries.

110. See COMMITTEE ON HUMAN GENOME DIVERSITY, *supra* note 98, at 27.

111. See *id.* at 36.

112. See *The Human Tissue Trade*, RAFI COMMUNIQUE (Rural Advancement Found. Int'l, Ottawa, Ont.), Jan.-Feb. 1997, at 9.

113. See *id.*

114. See COMMITTEE ON HUMAN GENOME DIVERSITY, *supra* note 98, at 71.

115. See *id.* at 71-72.

116. See *id.* at 73.

the HGDP itself, however, were considered in detail.<sup>117</sup> The British journal *Nature* (no doubt reading into the committee recommendations an exclusionary attitude towards research facilities outside of America—a “we-are-more-ethical-than-thou” attitude) interpreted the committee report as negative in its findings.<sup>118</sup> *Science*, on the other hand, proclaimed that the HGDP had received a green light, even though it remained financially unsupported.<sup>119</sup>

Recently, the HGDP received a small amount of funding from the MacArthur Foundation expressly to assist in improving communication with indigenous peoples who might participate in the research.<sup>120</sup> One or two such meetings have taken place, but at the recent conference in Montana devoted to genetic diversity, which was organized by indigenous peoples, not a single representative of the HGDP was present, even though they were invited.<sup>121</sup>

Meanwhile in 1997, the NIH, although unwilling to fund the HGDP because research into disease was not its primary purpose, developed a \$60 million project to examine human genetic diversity in the United States called the Environmental Genome Project, which is already in its first phase.<sup>122</sup> The stated objective of this research is to uncover the relationship between genetic susceptibility to disease and environmental factors, and its purpose is to develop “more aggressive disease prevention.”<sup>123</sup> This project will focus on 200 genes, making use of ethnically mixed, anonymous samples. Developments in molecular genetics have uncovered tantalizing scientific questions deemed worthy of immediate investigation. Despite the political dangers and ethical morass uncovered in connection with the HGDP as planned, research into genetic difference is a subject whose time has come.

117. *See id.* at 44-49.

118. *See* Collin MacIlwain, *Diversity Project “Does Not Merit Federal Funding,”* 389 *NATURE* 774, 774 (1997).

119. *See* Elizabeth Pennisi, *NRC OKs Long-Delayed Survey of Human Genome Diversity,* 278 *SCIENCE* 568, 568 (1997).

120. *See* North Am. Comm., Human Genome Diversity Project, *Frequently Asked Questions* (visited July 30, 1999) <<http://www.stanford.edu/group/morrinst/hgdp/faq.html>>.

121. The absence of all invited HGDP members was noted publicly at the conference, which I attended.

122. *See* National Inst. of Env'tl. Health Sciences, *EGP Overview* (visited July 30, 1999) <[wysiwyg://72/http://www.niehs.nih.gov/envgenom/concept.htm](http://www.niehs.nih.gov/envgenom/concept.htm)>.

123. *Id.*

## REGULATING SCIENCE

The Akwesasne Mohawk community has been subjected to numerous research projects of various kinds over many years resulting, in their words, in “the full range of beneficial to detrimental experiences.”<sup>124</sup> This community now has a standing research advisory committee, which systematically reviews all research protocols that have a bearing on their people.<sup>125</sup> Specifically with respect to genetic research, an Apache community in Oklahoma constituted a “tribal institutional review board” to examine a proposal for research involving their community.<sup>126</sup> A project investigating the genetic components of diabetes and prostate cancer, in which individuals volunteer to participate but anonymity is preserved, is now going ahead with community support.<sup>127</sup>

Clearly, we have entered an era when communities have decided to take it upon themselves to review and regulate the science that effects them directly. Nevertheless, with respect to genetic research, major concerns remain. For example, how can regulation be monitored and enforced, and, if it is, who will pay for it, particularly when so much research is initiated by the private sector?

Second, who “owns” genetic material? Individuals? Communities or tribal groups? Corporate organizations? Or humankind? Indigenous peoples for the most part have a preference for group ownership, whereas United States property law upholds individual ownership provided that body parts are not separated from the body in question.<sup>128</sup> Other people would argue that DNA cannot belong to anyone<sup>129</sup> or, alternatively, that it belongs to us all.<sup>130</sup> And yet others claim that ownership through patenting of body tissues and cells is essential if scientific research is to remain competitive.<sup>131</sup> Contracts drawn up in connection with genetic research focus on

124. AKWESASNE TASK FORCE ON THE ENV'T, RESEARCH ADVISORY COMMITTEE RESEARCH PROTOCOLS: A MODEL FOR TRIBAL PROTECTION (1996) (introduction) (on file with author).

125. *See id.*

126. *See* Morris W. Foster et al., *A Model Agreement for Genetic Research in Socially Identifiable Populations*, 63 AM. J. HUM. GENETICS 696, 698 (1998).

127. *See id.* at 696-702.

128. *See* BRETT LEE SHELTON, GENETIC RESEARCH AND NATIVE PEOPLES 4 (1998) (briefing to provide National Indian Health Board members with background information) (on file with author).

129. *See* Mead, *supra* note 87, at 48.

130. *See id.*

131. *See* Rebecca S. Eisenberg, *Genes, Patents, and Product Development*, 257 SCIENCE 903, 903 (1992).

entitlement, patenting, access, distribution, and uses to which genetic material may be put. In hammering out the terms of agreement of such contracts, radically different ontological perspectives about the human body and the uses to which body parts may be put can readily be discerned.

A third concern about genetic research, and the one that incites the most angst, deals with stigmatization, discrimination, and eugenics. Above all, investigations into genetic diversity are the greatest source of anxiety. It seems highly unlikely that well-informed indigenous groups will voluntarily cooperate with research about genetic diversity unless individual and group identity is rigorously protected, and communities are absolutely certain that ongoing legal negotiations with governments, most of them in connection with land claims, will in no way be jeopardized. The idea that humankind migrated out of Africa many thousands of years ago is an anathema to many indigenous peoples for two reasons. First, this account is in conflict with local accounts of events since "time immemorial." Second, any dislodging of the idea of "distinct" peoples will no doubt be used as a lever to reject land settlement claims.

Indigenous responses, most of them angry, to descriptions of Kennewick Man make it clear just how political this issue is.<sup>132</sup> Kennewick Man's skeleton, dating from more than 9000 years ago, was recently found near the Columbia River in the State of Washington.<sup>133</sup> It was described as having Caucasoid features, which, in the terminology of physical anthropologists, means exhibiting a specific cluster of biological features.<sup>134</sup> Use of this term is not limited to Caucasians, and Kennewick Man is not the first skeleton of this type found in North America.<sup>135</sup> In terms of forensics, most physical anthropologists argue that Kennewick Man closely resembles the Ainu, the aboriginal inhabitants of Japan.<sup>136</sup> Local Indian bands have demanded that this very complete skeleton, of enormous potential worth to scientists, be "repatriated" for burial, as has already happened to two other skeletons, one of which is over 10,000 years

132. See Jonathan Marks, *Replaying the Race Card*, 5 ANTHROPOLOGY NEWSL. 1, 1 (1988); Douglas Preston, *The Lost Man*, NEW YORKER, June 16, 1997, at 74, 74.

133. See Preston, *supra* note 132, at 70.

134. See *id.*

135. See *id.* at 70, 72.

136. See *id.* at 80.

old.<sup>137</sup> The Army Corps of Engineers, which is responsible for the stretch of land where Kennewick Man was found, has not thus far cooperated.<sup>138</sup> Most disturbing is that local tabloids and radio talk shows are referring to Kennewick Man as a “white man,” and have suggested that his discovery “changes everything with respect to the rights of Native Americans.”<sup>139</sup>

Clearly, with incidents such as these, if no argument can be made for direct benefit to the research population, Native American communities will in all probability reject projects dealing with genetic diversity. This means that only those projects limited to the investigation of disease causation and therapies are likely to be acceptable (although even for these projects no benefits can be assured, far from it). Research into genetic diversity that might enhance scientific knowledge more generally, specifically research that is related to human evolution and human migration patterns, can make no claims, it seems, to benefit anyone directly. Further, it threatens local wisdom. We are on treacherous ground here, sparring over competing creation stories. Without research into human evolution and archeology over the past 100 years, nineteenth century theories of social evolution that legitimated racist and sexist ideologies might still prevail as dominant discourse. Surely, benefit must be construed at times as something broader than individual, or even community gain?

What is certain is that projects as insensitive to human and ethical concerns as the HGDP has proved itself to be will do little but perpetuate exploitation and incite distrust and justified hostility on the part of indigenous peoples. The HGDP may well never get off the ground, but research initiated by the private sector is moving ahead rapidly with explorations of genetic diversity. If this behemoth cannot be made to respond to the concerns of indigenous peoples, then in the end it is probable that, aside from corporate profit and perhaps some new drugs on the market, we may not benefit much at all. On the contrary, all possibility of human affiliation across diverse groups, so urgently needed in this global era, may be irrevocably damaged.

137. *See id.* at 81.

138. *See id.* at 70, 81.

139. *See id.* at 81.

