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Debra Harry

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INDIGENOUS PEOPLES AND GENE DISPUTES

DEBRA HARRY*

INTRODUCTION

Wary from decades of exploitation in the name of science, Indigenous peoples typically approach any externally generated research agenda with caution, and for good reason. Indigenous peoples have been on the receiving end of research carried out in insensitive, and sometimes harmful, ways. Research has historically been a top-down, outside-in process, with Indigenous peoples serving merely as research subjects, not partners, without any meaningful participation or potential to benefit from outcomes of the research.

Over the past decade there has been a dramatic increase in genetic research projects that put Indigenous peoples front and center of the research process. Geneticists' interests in Indigenous peoples' DNA are many. Indigenous peoples' DNA is sought for medical, behavioral, large-scale human population studies, and ancient DNA genetic research.

This article will give a few examples of Indigenous peoples' experience with human genetic research, identify some of the common issues that arise for Indigenous peoples in relation to genetic research, and discuss the need and options for the protection of Indigenous peoples' rights and inter-

* Debra Harry, Ph.D., is Northern Paiute from Pyramid Lake, Nevada, USA. She is the Executive Director of the Indigenous Peoples Council on Biocolonialism (IPCB). Debra is the producer of an IPCB/Yeast Directions documentary film "The Leech and the Earthworm," which captures the perspectives of various Indigenous leaders about the impacts of genetic technologies on Indigenous peoples. Debra's areas of expertise include protection of Indigenous peoples' genetic resources, Indigenous knowledge, and cultural and human rights. She earned her doctorate at the University of Auckland, Faculty of Education.

ests.

I. INDIGENOUS PEOPLES' EXPERIENCE

A. Medical Genetic Research

Many of the health conditions from which we suffer today are complex conditions caused largely by the interaction between our biology and various social, economic, and environmental conditions. While they may have some genetic component, conditions such as Type 2 diabetes, heart disease, and cancer are not wholly caused by genes, and as such, no amount of genetic research can provide a cure.

Unfortunately, Indigenous peoples have experienced exploitation as a result of participating in medical research when genetic samples they provided were later used in non-consensual secondary research.

1. Pima and Type 2 Diabetes Research

In the field of medical genetic research on conditions related to human health, Indigenous peoples have been frequently studied for their high rates of diabetes. For example, a geneticist researching the Tohono O'Odham, also known as the Pima Indians of Arizona (located in the U.S. Southwest), who are said to have the world's highest prevalence of Type 2 diabetes, once postulated that this condition was due to a unique Piman gene¹ But scientists now widely recognize that Type 2 diabetes is a "complex disease that afflicts peoples from all ethnic backgrounds" and has many "environmental factors, including high-fat, low-fiber, and high-carbohydrate diets, in addition to a sedentary lifestyle."² As biologist Dr. Ruth Hubbard explains:

All of this research is being done in the hope of finding a predictive test for a "predisposition" to develop a condition that many people could avoid by changing their diets and getting regular exercise. Surely, it would be better to educate everyone about the importance of diet and exercise and to work toward providing the economic and social conditions that could enable more people to live healthily, rather than spending time and money trying to find "aberrant" alleles and to identify individuals whose genetic constitution may (but then again, may not) put them at

1. Stuart A. Newman, *The Role of Genetic Reductionism in Biocolonialism*, 12 PEACE REV. 517, 521 (2000).

2. Jeffrey C. Long & Joseph G. Lorenz, *Culture and Medicine: Genetic Polymorphism and American Indian Health*, 176 W. J. MED. 203, 204 (2002); see also RUTH HUBBARD & ELIJAH WALD, *EXPLODING THE GENE MYTH* 76 (1999).

special risk.³

Dr. Stuart Newman, Professor of Cell Biology and Anatomy at New York Medical College, discusses how diabetes has needlessly been a focus of genetic research among the Tohono O'Odham:

Groups such as the Pima Indians, which didn't have much diabetes 75–80 years ago, now get it in large numbers. Not only are they being sold genetically engineered insulin as a palliative, but they're also being told that their problem is in their genes (such as having an entirely hypothetical "thrifty gene"). Whatever inherent susceptibilities the Pima may have to the bad diet that has been forced on them, their genes certainly have not changed significantly in the last 75 years. Thus, we should be wary of genetic explanations and quick medical fixes for diseases that might ultimately be social problems.⁴

Similarly, Dr. Ruth Hubbard also is wary of the increasing searches for a genetic basis for environmentally induced health conditions, stressing that "the myth of the all-powerful gene is based on flawed science that discounts the environmental context in which we and our genes exist."⁵ Dr. Hubbard is concerned that, "speculations about genetic 'predispositions' distract people from the need to make environmental . . . changes"⁶

With regard to familial genetic research, even when genes are suspected to be involved in a particular health condition, it often is only one of many possible factors in the disease process.⁷ This is true in particular with complex trait conditions such as cancer or diabetes, in which case there are multiple factors and the condition is not simply genetic.⁸ Dr. Ruth Hubbard explains:

There are indeed some conditions for which genes are fairly predictive. People who inherit the gene associated with sickle cell anemia from each of their parents are almost sure to have sickle cell anemia. They don't have symptoms all the time, but they are likely to have them if the oxygen content of their blood drops below a critical level. Similarly people who inherit the gene associated with PKU, or phenylketonuria, from both their parents will experience the symptoms of PKU, but again only under specific conditions, in this case if they eat foods containing the amino acid phenylalanine.⁹

Even such . . . predictive genes are not prescriptive. Their effects are only expressed under specific conditions and may involve other,

3. HUBBARD & WALD, *supra* note 2, at 77.

4. Newman, *supra* note 1, at 521.

5. HUBBARD & WALD, *supra* note 2, at 6.

6. *Id.* at 91.

7. *Id.* at xxi.

8. *Id.*

9. *Id.*

seemingly quite unrelated genes or things happening elsewhere in the body or in our lives.¹⁰

Another factor here is that despite the identification of genes for these conditions there is still no cure available.

The key point here is that, oftentimes, medical genetic research involving Indigenous peoples is not necessarily research that will have medical benefits. Typically, medical genetic research involving Indigenous peoples is structured around culturally identifiable populations, rather than the more usual familial lineages. Overlaying genetic research with culturally identifiable group labels, which have no direct correlation with biology, is not medically useful and unnecessarily implicates the entire cultural group in a process that should focus on individuals with or without a particular health condition.

The Pima study indicates how genetic research, even when labeled as medical research, may not—and may never be able to—deliver the hoped-for outcomes for Indigenous peoples.

2. Havasupai Tribe

For several years now, the Havasupai Tribe and individual tribal members have been embroiled in the aftermath of unauthorized genetic research performed under the guise of diabetes research. The Havasupai Tribe based in northern Arizona provided their blood for use in diabetes research, but later found out it was used for studies on schizophrenia, inbreeding, and ancient-human migration studies.¹¹ The Havasupai Tribe says that their lives were “forever changed” when their “sacred blood” was taken from them, by researchers at Arizona State University and the University of Arizona, for what ended up being research without consent on “schizophrenia, inbreeding, and to support the ‘Bering Strait Theory’” of ancient-human migration.¹²

In geographically isolated tribes, such as the Havasupai, whose reservation located at the bottom of the Grand Canyon can only be accessed by

10. *Id.*

11. Havasupai Tribe, A Case of Genetic Piracy, <http://www.geneticpiracy.com> (last visited Apr. 30, 2009). The Arizona State University’s own investigative findings into the case discovered that “[s]amples were distributed to other institutions and research was done using them, which was not related to diabetes.” STEVEN HART & KEITH A. SOBRASKE, INVESTIGATIVE REPORT CONCERNING THE MEDICAL GENETICS PROJECT AT HAVASUPAI 3 (2003), available at <http://www.geneticpiracy.com/Documents/HartReport.pdf>.

12. Havasupai Tribe, *supra* note 11.

foot or horseback,¹³ some scientists see unique gene pools that represent a “gold mine” for their research. Beginning in 1990, scientists took 400 Havasupai blood samples to study their high incidence of Type 2 diabetes, but later used the same samples to conduct unauthorized research on other topics.¹⁴ The Tribe says this further research contradicts their spiritual beliefs and has caused “grave emotional duress and mistrust.”¹⁵ To shield themselves from further exploitation, the Havasupai Tribe has placed a moratorium on biomedical research on their reservation. The Havasupai’s reaction to their experience has been characterized by the lead researcher and defendant, Dr. Therese Markow, as “hysterical”¹⁶ and by *Nature*, a well-known science periodical, as “hypersensitive.”¹⁷ However, the Havasupai have received the support of many tribes and inter-tribal organizations including the Inter Tribal Council of Arizona, whose resolution “condemns all unauthorized genetic research on Native American Indian Tribes and calls upon Arizona State University to resolve the Havasupai’s claims promptly and appropriately,”¹⁸ and the National Congress of American Indians (NCAI), the oldest and largest national organization of American Indian and Alaska Native tribal governments, which states the “NCAI supports the Havasupai Indian Tribe litigation because many tribes have been similarly affected, and the case may set precedent that affects the rights of all Indian tribes.”¹⁹

In two separate cases filed in 2004, one on behalf of several individual tribal members²⁰ and another on behalf of the Tribe,²¹ the Havasupai brought claims against the scientists, universities, and Board of Regents listing a number of causes of action, including: (1) breach of fiduciary duty

13. *Id.*

14. Charlie Furniss, *Blood Feud*, GEOGRAPHICAL, Sept. 2006, at 43, 44; Havasupai Tribe, *supra* note 11.

15. Havasupai Tribe, *supra* note 11.

16. Anne Minard, *UA Scientist Named in Two Suits by Havasupai Tribe, Members*, ARIZ. DAILY STAR, Mar. 24, 2005, http://www.nathpo.org/News/Tribal/News-Tribal_Governments37.html.

17. *Tribal Culture Versus Genetics*, 430 NATURE 489, 489 (2004).

18. INTER TRIBAL COUNCIL OF ARIZONA, RESOLUTION 0603: SUPPORT FOR THE HAVASUPAI INDIAN TRIBE para. 8 (2006), available at http://www.geneticpiracy.com/Documents/InterTribal_CouncilofAZ.pdf.

19. Nat’l Congress of Am. Indians, Resolution SAC-06-019: Supporting the Havasupai Indian Tribe in their Claim Against the Arizona Board of Regents Regarding the Unauthorized Use of Blood Samples and Research para. 11 (2006), available at <http://ncai.org/ncai/resolutions/doc/SAC-06-019.pdf>.

20. *Tilousi v. Ariz. State Univ. Bd. of Regents*, No. 04-CV-1290-PCT-FJM, 2005 WL 6199562 (D. Ariz. Mar. 3, 2005) (slip. op.), available at: <http://www.whoownsyourbody.org/havasupai.html>.

21. *Havasupai Tribe of Havasupai Reservation v. Ariz. Bd. of Regents*, Nos. 1 CA-CV 07-0454, 1 CA-CV 07-0801, 2008 WL 5047641 (Ariz. Ct. App. Nov. 28, 2008) (consolidated action).

and lack of informed consent; (2) fraud and misrepresentation/fraudulent concealment; (3) intentional or negligent infliction of emotional distress; (4) conversion; (5) violation of civil rights; and (6) negligence, gross negligence and negligence per se.²² Subsequent court action dismissed three of the causes of action allowing the Havasupai to continue their case for the infliction of emotional distress, violation of civil rights, and negligence claims.²³ The Havasupai voluntarily dismissed their federal civil rights claim, stripping the federal court of jurisdiction to hear the case, and the case went back to Arizona state court where the two cases were merged.²⁴ The case was pending in Maricopa County Superior Court where the Havasupai pled four causes of action: (1) breach of confidential or fiduciary duty (including lack of informed consent); (2) fraud and misrepresentation/fraudulent concealment; (3) negligence, gross negligence, negligence per se; and (4) trespass (with respect to the blood samples and entry onto tribal lands).²⁵ The lower court dismissed the action on technical grounds, but on November 28, 2008, the Court of Appeals of Arizona reversed the dismissal and remanded the case.²⁶

The situation that befell the Havasupai Tribe exemplifies many of the ways researchers can disrespect tribes in the course of research, including breach of trust, lack of informed consent, allowing secondary uses of samples with unauthorized researchers, and unauthorized publications.

3. Nuu-chah-nulth Story

In 2002, the Nuu-chah-nulth Tribe in British Columbia was outraged to find that samples taken for arthritis research at the University of British Columbia (UBC) in the early 1980s were still being used at Oxford University in England for unrelated research without their consent.²⁷ By the time the researcher Dr. Ryk Ward left UBC in 1986, he took almost 900 samples of Nuu-chah-nulth blood with him.²⁸ He utilized the Nuu-chah-nulth sam-

22. *Tilousi*, No. 04-CV-1290-PCT-FJM 2005 WL 6199562, at *2-*6 (D. Ariz. Mar. 3, 2005) (Order granting in part Defendant's Motion to Dismiss), available at <http://whooownyourbody.org/havasupai-arizona.pdf>.

23. *Id.* at *6-*7.

24. *Havasupai*, 2008 WL 5047641, at *1.

25. Second Amended Complaint at 23-33, *Havasupai Tribe of Havasupai Reservation v. Ariz. Bd. of Regents*, No. CV2005-013190, 2006 WL 4642880 (Ariz. Super. Ct. Feb. 22, 2006).

26. *Havasupai*, 2008 WL 5047641, at *18 (reversing trial court dismissal and remanding the case for further proceedings).

27. *Blood Promise*, CBC.CA, Sept. 27, 2000, http://www.cbc.ca/news/story/2000/09/27/bc_blood000927.html.

28. David Wiwchar, *Nuu-chah-nulth Blood Returns to West Coast*, HA-SHILTH-SA (Canada), Dec.

ples in subsequent genetic anthropology-related research, which resulted in hundreds of published papers, and an appointment as head of the Institute of Biological Anthropology at Oxford University.²⁹ In 2004, after Dr. Ward's death the prior year, Oxford University returned the blood samples and records to UBC.³⁰ A Nuu-chah-nulth research ethics board will oversee any use of the samples in future research.³¹ Even though the samples have finally been repatriated, the Nuu-chah-nulth will continue to explore legal options to seek liability and compensation in this case of abject exploitation.³²

B. Behavioral Genetic Research

In the field of behavioral genetics, scientists have published studies that propose a genetic basis for high rates of alcoholism among some Native American tribes.³³ However, other researchers note that "no evidence currently exists that the prevalence of alcoholism or its transmission in families can be attributed to unique features of the American Indian gene pool."³⁴

Other research proposes a genetic basis for violent and aggressive behaviors in the Maori people in Aotearoa/New Zealand.³⁵ Dr. Rod Lea, a genetic epidemiologist at the New Zealand Institute of Environmental Science and Research, claims that Maori men have a "'striking overrepresentation' of monoamine oxidase - dubbed the warrior gene" which he says "means [the Maori] are going to be more aggressive and violent and more likely to get involved in risk-taking behaviour like gambling."³⁶ Lea also postulates that high rates of binge drinking and smoking among the Maori are also linked to this gene.³⁷

16, 2004, at 1, available at [http://caj.ca/mediamag/awards2005/\(David%20Wiwchar,%20Sept.%202012,%202005\)Blood2.pdf](http://caj.ca/mediamag/awards2005/(David%20Wiwchar,%20Sept.%202012,%202005)Blood2.pdf).

29. *Id.*

30. *Id.* at 3.

31. *Id.*

32. *Id.* at 4.

33. Jamie Talan, *The Search for Genetic Keys to Alcoholism Research: Scientists Hope That by Understanding the Disease Better, They Can Develop More Effective Treatments*, L.A. TIMES, May 21, 2001, at S1 (discussing studies on Native American tribes in the Southwest that found that genetic contribution to alcoholism might be as high as 85%).

34. Long & Lorenz, *supra* note 2, at 205.

35. *Once Were Warriors: Gene Linked to Maori Violence*, SYDNEY MORNING HERALD, Aug. 9, 2006, <http://www.smh.com.au/news/world/once-were-warriors-gene-linked-to-maori-violence/2006/08/08/1154802890439.html>.

36. *Id.*

37. *Id.* See also *Gene Stokes Smoking Addiction*, N.Z. HERALD, Feb. 24, 2005,

In response to announcements about the “warrior gene,” one of Lea’s fellow New Zealand geneticists questioned the ethics involved in linking a gene to a race.³⁸ Furthermore, the Maori themselves were quick to note that the research reinforced stereotypes of violence among the Maori and denounced the “warrior gene” research, citing “social issues, including high unemployment, poor educational achievement and in many cases severe poverty, to be the main contributors to Maori violence rather than a warrior gene.”³⁹

Over-emphasis on genetic causation can bring stigmatization to the groups as being somehow inherently flawed, and it ignores the many non-genetic factors at work.⁴⁰ Such population-based research outcomes are statistical and inconclusive in nature. As Richard Lewontin notes, “[r]acist scientists produce racist science,” perhaps not deliberately, but that “their unconscious prejudices lead them to largely unconscious biases in their methods and analysis, biases that bring them comfortable conclusions.”⁴¹

In both of these examples, the research is not only focused on identifiable cultural groups, but also attempts to link genes with behavior, as if alcoholism, violence, binge-drinking, over-eating, incessant shopping, or smoking are innate. Indigenous peoples have suffered centuries of colonization and oppression, and thus assertions that certain behaviors are genetically based disregard the impacts that colonial and environmental abuses—such as dispossession from land, loss of language and culture, poverty, environmental contamination, and associated social ills—have on drinking, smoking, or violent behavior.

C. Large-Scale Population Based Genetic Research

1. Human Genome Diversity Project

The Human Genome Diversity Project (HGDP), a global study on human genetic variation initiated in 1991 by human population geneticist Luigi Luca Cavalli-Sforza and a cadre of other scientists around the world, sought to collect blood samples from 700 targeted Indigenous peoples re-

http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=10112375.

38. Jon Stokes, *Maori 'Warrior Gene' Claims Appalling, Says Geneticist*, N.Z. HERALD, Aug. 10, 2006, http://www.nzherald.co.nz/health/news/article.cfm?c_id=204&objectid=10395491.

39. *Maori Slam 'Warrior' Gene Study*, AUSTL. BROADCASTING CORP. Aug. 9, 2006, http://www.abc.net.au/science/news/health/HealthRepublish_1710435.htm.

40. See Long & Lorenz, *supra* note 2, at 205.

41. RICHARD LEWONTIN, *IT AIN'T NECESSARILY SO: THE DREAM OF THE HUMAN GENOME AND OTHER ILLUSIONS* 11 (2000).

ferred to as "Isolates of Historical Interest."⁴² The HGDP was rife with numerous intractable ethical issues that ultimately led to its demise in the late 1990s. Nonetheless, the National Science Foundation continued to fund HGDP pilot projects and other genetic diversity projects throughout the National Research Council's review process.⁴³ The Canadian-based non-governmental organization Rural Advancement Foundation International (RAFI) reported that:

Total support from the NSF's Physical Anthropology Program for human biodiversity activities nearly doubled between 1995 and 1997. Between the time the NSF commissioned the HGDP evaluation in mid-1995 and the time the NRC committee tendered its report rejecting the HGDP as a viable project . . . the NSF disbursed \$2,197,832 in 21 grants related to human genetic diversity research and/or collection [of genetic samples]. Of that, \$1,143,748 (or 52%) went to 10 HGDP activities.⁴⁴

The HGDP was vigorously opposed by Indigenous peoples until it was ultimately defeated in the late 1990s.⁴⁵ As the first global genetic research effort targeting Indigenous peoples, the HGDP forced Indigenous peoples, including myself, to get a genetics education as quickly as possible. We learned from the HGDP that it is not possible to separate the science from the ethics and human rights issues. That experience and activism produced a number of well-informed Indigenous leaders around the world who have been quick to take a critical look at the goals and methodology of many different genetic research projects. Several of these projects, Indigenous analyses, and critiques are covered in this article.

2. The Genographic Project

In April 2005, the National Geographic Society (NGS) announced its partnership with the IBM Corporation to launch the Genographic Project.⁴⁶ The five-year, fifty-five million dollar project is funded by the Waitt Family of the Gateway Computers fortune.⁴⁷ According to lead geneticist

42. JENNY REARDON, *RACE TO THE FINISH: IDENTITY AND GOVERNANCE IN AN AGE OF GENOMICS* 68 (2005).

43. Press Release, Rural Advancement Foundation International, *US Funding of Human Biodiversity Collections Carries on Despite Contrary Scientific Advice* (Nov. 14, 1997), *available at* http://www.etcgroup.org/en/materials/publications.html?pub_id=434.

44. *Id.*

45. Furniss, *supra* note 14, at 49.

46. National Geographic, *The Genographic Project, Frequently Asked Questions: About the Project* ¶¶ 1, 3, https://genographic.nationalgeographic.com/genographic/lan/en/faqs_about.html (last visited Apr. 30, 2009).

47. National Geographic, *The Genographic Project, Frequently Asked Questions: Funding and Partners* ¶¶ 1, 6, https://genographic.nationalgeographic.com/genographic/lan/en/faqs_funding.html (last

Spencer Wells, the purpose of the project is “to trace human roots from the present day back to the origin of our species,” by creating “a virtual museum of human history.”⁴⁸ More specifically, the virtual museum would be comprised of 100,000 DNA samples taken from Indigenous peoples around the world.⁴⁹ With this project, the NGS will not only collect images and cultural data, but will also carry out the more invasive practice of collecting blood from Indigenous peoples around the world.⁵⁰ The Genographic Project is a highly invasive continuation of the NGS’s practice of exploiting, objectifying, and capitalizing on the lives of Indigenous peoples.

The Genographic Project is reminiscent of the failed HGDP. Although the Genographic Project has tried to distance itself from the HGDP, both projects share similar goals and intellectual leadership. Principal investigator and lead geneticist Dr. Spencer Wells once worked with HGDP founder Luigi Luca Cavalli-Sforza, who now serves on the International Advisory Board of the Genographic Project.⁵¹ Cavalli-Sforza believes that the Genographic Project is almost the same as the HGDP.⁵² Yet, Dr. Wells insists the project differs from the HGDP because it is non-commercial, will not do any medical research, and will not create any cell lines from the DNA samples.⁵³ However the HGDP also did not intend to capitalize from its research or perform medical research. And with or without cell lines, the samples taken from Indigenous peoples will provide a long lasting supply of DNA for research in the long-term. The only significant difference is that the Genographic Project is a private enterprise, and thus, does not have to undergo the same depth of public scrutiny as the HGDP, which sought federal funding and, therefore, had to meet federal ethics standards.

Many of the ethical issues that the HGDP was unable to address have been considered in scholarly literature, yet the Genographic Project has only minimally addressed these issues.⁵⁴ For instance, one of the most im-

visited Apr. 30, 2009).

48. Claudia Kalb, *In Our Blood: DNA Testing*, NEWSWEEK, Feb. 6, 2006, at 46, available at <http://www.newsweek.com/id/57201>.

49. *Id.*

50. National Geographic, The Genographic Project, Frequently Asked Questions: Testing and Results ¶ 1, https://genographic.nationalgeographic.com/genographic/lan/en/faqs_results.html#Q1 (last visited Apr. 30, 2009).

51. Meredith F. Small, *First Soldier of the Gene Wars*, ARCHAEOLOGY, May/June 2006, at 46, 51.

52. *Id.*

53. National Geographic, The Genographic Project, Frequently Asked Questions: About the Project ¶ 7, https://genographic.nationalgeographic.com/genographic/lan/en/faqs_about.html#Q7 (last visited Apr. 30, 2009).

54. See, e.g., REARDON, *supra* note 42.

portant lessons learned from the HGDP is that in the realm of human research, it is not possible to separate science from ethics and human rights issues—and that may be where the Genographic project went wrong from the beginning. The Genographic Project seems to take individual informed consent as sufficient justification to proceed.⁵⁵ However, the National Academy of Science noted in its evaluation of the HGDP:

Consent alone cannot justify research on populations that will not be able to benefit from it because such research violates basic principles of social justice and equality. Research subjects can make a gift to researchers or humanity, but the validity of such a gift in the context of studying genetic diversity, especially of isolate populations, is too problematic to provide the sole justification for the research.⁵⁶

The conclusion is that unless the risk-benefit ratio is in favor of the populations to be studied, the research protocol is not ready for institutional review board (or any other) ethical review.⁵⁷

The Genographic Project is trying to induce Indigenous peoples to participate in the Project by establishing “The Legacy Fund.” The Fund proposes to donate a portion of the proceeds derived from the sale of cheek swabs kits sold to the general public for Indigenous peoples’ cultural preservation projects.⁵⁸ Schemes such as the Legacy Fund are contrived in order to create a benefit when the research itself does not directly benefit the research subjects. The Legacy Fund is a coercive tool developed to entice the participation of Indigenous peoples.

Upon its announcement, the Genographic Project drew swift criticism from Indigenous peoples. The Indigenous Peoples Council on Biocolonialism (IPCB) initiated a global petition calling for an immediate halt to the Project and a moratorium on NGS and IBM products citing numerous ethical and cultural concerns.⁵⁹ This petition, with over 850 signatures from Indigenous peoples’ organizations, individuals, and supporters, was pre-

55. National Geographic, The Genographic Project, Frequently Asked Questions: About the Project 2, https://genographic.nationalgeographic.com/genographic/lan/en/faqs_about.html#Q2 (last visited Apr. 30, 2009).

56. COMM. ON HUMAN GENOME DIVERSITY, NAT’L RESEARCH COUNCIL, EVALUATING HUMAN GENETIC DIVERSITY 59 (1997).

57. Debra Harry & Le’a Malia Kanehe, *Collecting Blood to Preserve Culture?*, CULTURAL SURVIVAL Q., Winter 2006, at 34, 36.

58. National Geographic, The Genographic Project, Frequently Asked Questions: The Genographic Legacy Fund ¶ 2, https://genographic.nationalgeographic.com/genographic/lan/en/faqs_legacy_fund.html (last visited Apr. 30, 2009).

59. Indigenous peoples have petitioned for a global boycott of the National Geographic Society, IBM Corporation, and Gateway Computers until this project is halted. INDIGENOUS PEOPLES COUNCIL ON BIOCOLONIALISM, PETITION TO OPPOSE THE GENOGRAPHIC PROJECT (2006), http://www.ipcb.org/issues/human_genetics/htmls/gp_petitionsigs.html.

sented in person to the Genographic Project staff at a May 2006 meeting in New York City.⁶⁰

Across the street, in the halls of the United Nations, these concerns were echoed by an international expert body, the United Nations Permanent Forum on Indigenous Issues (UNPFII), in its recommendation that “the World Health Organization (WHO) and the Human Rights Commission investigate the objectives of the Genographic Project.”⁶¹ Most significantly, the UNPFII also requested “that the Genographic Project . . . be immediately suspended and . . . report to indigenous peoples on the free, prior and informed consent of indigenous peoples in all the communities where activities are conducted and planned.”⁶²

Cultural Survival, an organization dedicated to supporting Indigenous and human rights, urged the NGS to place a moratorium on the Project “until indigenous peoples’ concerns are fully considered and addressed, the international indigenous rights movement endorses the Project’s goals and methods, and independent verification systems that ensure that the Project causes no harm to indigenous people, their ancestors, or their descendents are put in place.”⁶³ The Council for Responsible Genetics, one of the oldest and most highly respected civil society organizations comprised of scientists and other experts who monitor genetic issues, also issued a statement calling upon the Genographic Project to suspend its operations, citing, “[t]he failure to consult with the indigenous peoples has resulted in the Project’s violation of the fundamental ethical principles of DNA-based research, which cannot be treated as if it is just another National Geographic photo shoot.”⁶⁴

Despite the widespread opposition advanced by Indigenous peoples and our supporters, the Genographic Project seems hardly fazed. In fact, it seems the project’s organizers may have increased their collection efforts with a renewed urgency.

In May 2005, just one month after its public launch, the University of Pennsylvania Social and Behavioral Sciences Institutional Review Board

60. *Id.*; Furniss, *supra* note 14, at 51.

61. U.N. ECON. & SOC. COUNCIL [ECOSOC], *Permanent Forum on Indigenous Issues*, ¶ 88, U.N. Doc. E/C.19/2006/11 (May 15–26, 2006); available at http://www.un.org/esa/socdev/unpfii/en/session_fifth.html.

62. *Id.*

63. Letter from Ellen Lutz, Stella Tamang & Richard Grounds, members, Cultural Survival, to The Nat’l Geographic Soc’y (July 26, 2006) (on file with author).

64. Press Release, Council for Responsible Genetics, *The Genographic Project Should Be Suspended Until Concerns Are Addressed* (Jan. 9, 2006), available at <http://gene-watch.org/programs/privacy/RGPressRelease.html>.

approved the Genographic Project's research protocol, authorizing the Project to commence its North American branch. The University of Pennsylvania's Institutional Review Board is responsible for ethical review of the research protocol in the region. However, in the summer of 2006, the Genographic Project took samples from Alaska Natives without approval from the Alaska Area Institutional Review Board, which is responsible for ensuring oversight of human subject research involving Alaska Natives. As a result, the University of Pennsylvania Institutional Review Board temporarily withheld approval, and the protocol is undergoing review by the institution's review boards. Subsequently, the Alaska Area Institutional Review Board demanded that the North American principal investigator, Dr. Theodore Schurr, return the Alaskan Native samples, and undertook its own critical review of the Genographic Project's research protocol.⁶⁵ The North American research protocol serves as the basis for the protocols at the nine other regional research centers.

One of the Genographic Project's more recent developments includes an high-end tourism offering for the well-heeled tourist.⁶⁶ Jonathan Marks has nicknamed this new venture "Adventures in Hemo-Tourism," stating, "just when you thought human population genetics could not get any more weird or embarrassing, they still manage to surprise you."⁶⁷ "National Geographic Expeditions now offers the 'Journey of Man by Private Jet' tour, from April 23–May 17, 2008."⁶⁸

In an article published in the December 2007 issue of *Anthropology News*, Marks describes the Genographic Project's Hemo-Tourist travel brochure:

Travel in comfort as our VIP-outfitted Boeing 757 whisks us to ten extraordinary destinations in China, Mongolia, Cambodia, Australia, Papua New Guinea, Malaysia, South India, Southern Africa, Tanzania, and Central France" . . . You will begin by meeting Mongolians whose DNA is descended from Genghis Khan, move on to Australia and meet some Aborigines, to Papua New Guinea and Borneo, to India to "meet the man who holds the missing genetic link that helped Spencer establish our early ancestors' migration from Africa to Australia," to Africa to meet "San Bushmen, who represent a direct link to our earliest ancestors" and "the world's last surviving groups of hunter-gatherers." And when you have had your fill of remote poor people, you end up in the Dordogne, to

65. Amy Harmon, *DNA Gatherers Hit a Snag: The Tribes Don't Trust Them*, N.Y. TIMES, Dec 10, 2006, <http://query.nytimes.com/gst/fullpage.html?res=9407E0DD1431F933A25751C1A9609C8B63>.

66. Jonathan Marks, *Adventures in Hemo-Tourism*, ANTHROPOLOGY NEWS, Dec. 2007, at 3, 3–4.

67. *Id.*

68. *Id.* at 4.

dine on the indigenous cuisine of Perigord truffles.⁶⁹

Marks closes his article:

And the cost for traveling around the world in luxury to visit exotic peoples and pretend to be their kin? It can all be yours for \$50,000. If you want a single room, that is \$7,500 more, and they will still hit you up to donate \$2,000 to keep the Genographic Project running, because it is such a good cause.⁷⁰

With ten centers around the world, including in Brazil, Australia and China, many more Indigenous peoples have or will become research subjects. However, the Genographic Project has refused to be transparent and produce a list of targeted populations, by claiming confidentiality of the research subjects—except maybe to the fifty thousand dollar-paying Hemo-Tourists.

Indigenous opposition to the Genographic Project has been characterized as “uninformed” and “anti-science;”⁷¹ however, the concerns of Indigenous peoples are based on sound ethical, legal, and cultural arguments.

Wells has attempted to minimize the weight of the petition against the Genographic Project by saying that “[t]here are an estimated 300 million indigenous people in the world today, so 868 isn’t a huge number. On the other hand, we have 8,000-plus indigenous people from around the world who have already participated.”⁷² Wells further dismisses the signatories of the petition as “academics or indigenous rights advocates, and not from indigenous people per se.”⁷³ The UNPFII’s chairwoman, Victoria Tauli-Corpuz, a long-time Indigenous rights advocate, disagrees with Wells’ rationalization and believes that such an explanation is somewhat disingenuous. Specifically, the fact that the UNPFII’s members and the signatories of the petition hold a different point of view is exactly what makes their opinion so important: “There are many implications of these projects that communities are not always aware of. I would be very interested to know, for example, whether the Genographic Project warns participants about the potential threats to their land security.”⁷⁴ She further notes that “representatives of indigenous institutions who are aware of all of the im-

69. *Id.*

70. *Id.*

71. Small, *supra* note 51, at 51 (quoting Luca Cavalli-Sforza who dismisses the protesters against the Human Genome Diversity Project and the Genographic Project as “people who hate biology . . . or they hate humanity”).

72. Furniss, *supra* note 14, at 52.

73. *Id.*

74. *Id.*

plications should be involved in the consent process.”⁷⁵

The truth is that many of the signatories of the petition and members of the UNPFII are indeed long-time Indigenous rights advocates. Many of them are drafters and advocates for the adoption of the United Nations Declaration on the Rights of Indigenous Peoples, which has now been adopted by the United Nations General Assembly and is recognized as setting the minimum standard for the protection of Indigenous rights. As Tauli-Corpuz noted, it is precisely the opposite that makes these signatures important. A careful look at the signatories to the petition reveals Indigenous leaders who, in addition to the work they do for their peoples locally, are those individuals who advocate in international standard-setting debates in the United Nations Convention on Biodiversity, the World Intellectual Property Organization (WIPO), the World Trade Organization (WTO), and the World Bank, to name a few. These few warriors do the work on behalf of the millions of Indigenous peoples without a voice. These experts are saying that the Genographic Project raises serious concerns for the rights of all Indigenous peoples. That voice cannot be taken lightly, and should not be ignored.

The IPCB hoped the campaign work and the weight of a United Nations recommendation would cause the NGS to seriously reconsider moving forward with this project. However, it has not. It is apparent that the Genographic Project is committed to steamroll ahead with its efforts.

The case studies below illustrate the very real and contemporary cases where this clash of knowledge is being played out in a harmful manner for tribes.

3. Ancient DNA Study

In molecular anthropology, researchers use Indigenous DNA to develop theories of ancient-human migrations.⁷⁶ A recent book about the “Peopling of North America” reveals a multitude of molecular anthropology studies using the DNA of North American Indigenous peoples to support various theories on migrations to the continent.⁷⁷ Essentially, in this type of research, scientists posit theories cloaked in evidentiary terminology that Indigenous peoples of North America all came from Asia, through Siberia, and over the Bering Strait land bridge into modern day Alaska and

75. *Id.* at 53.

76. PETER N. JONES, *AMERICAN INDIAN mtDNA, Y CHROMOSOME GENETIC DATA, AND THE PEOPLING OF NORTH AMERICA 3* (2004).

77. *Id.* at 107–217.

then dispersed across the continent.⁷⁸

An aspect of anthropological genetics involves the analysis of what is known as “ancient DNA,” which is taken from human remains and compared to DNA from contemporary populations in the same geographic area.⁷⁹ Many tribes consider this type of destructive analysis a desecration of ancestors, and as a result, many tribes have taken a strong stand against this type of research.⁸⁰ The Eastern Band of Cherokee has adopted a law that recognizes the graves of Cherokee people as “sacred” and specifically prohibits “destructive skeletal analysis.”⁸¹ Furthermore, tribes should also be aware that anthropological geneticists may assert theories about migrations and origins that are different than those in which tribes believe, based on their oral histories.⁸²

The study of ancient remains is a highly sensitive and emotional issue for Indigenous peoples and one that cuts right to the heart of the debates of racism in scientific research and on respect for the rights, humanity, and human dignity of Indigenous peoples and their ancestors.

a. NAGPRA and Scientific Interest

The Native American Graves Protection and Repatriation Act (NAGPRA) is a federal law designed to assist tribes in repatriating the remains of their ancestors, and other sacred items, being held in museums—a term of art under NAGPRA that excludes the Smithsonian Institution and federal agencies from coverage⁸³ NAGPRA represents a compromise between the interests of scientists in research, the property interests of museums in their collections, and the human rights interests of tribes in returning the remains of their ancestors to a final resting place.⁸⁴

Recently, much interest has been generated in the prospect of using

78. *Id.* at 134–35.

79. *Id.* at 60.

80. INDIGENOUS PEOPLES COUNCIL ON BIOCOLONIALISM, BRIEFING PAPERS: THE INAPPROPRIATE USE OF GENETIC ANALYSIS IN REPATRIATION (2006), http://www.ipcb.org/publications/briefing_papers/index.html (last visited July 6, 2009) (discussing tribes taking a stand against ancient DNA taken and studied against contemporary populations).

81. THE CHEROKEE NATION CODE § 70-1(a), (c) (2008).

82. HART & SOBRASKE, *supra* note 11, at 3 (discussing how investigative findings that published papers using Havasupai samples drew inferences about the Tribes’ migration to the Americas, which were used in press coverage to contrast Native American beliefs).

83. Native American Graves Protection and Repatriation Act (NAGPRA), 25 U.S.C. §§ 3001–3013 (2006).

84. Jack F. Trope & Walter R. Echo-Hawk, The Native American Graves Protection and Repatriation Act: Background and Legislative History, 24 ARIZ. ST. L.J. 35, 60 (1992).

DNA “evidence” in the context of repatriation. Two potential purposes are cited: first, DNA might be useful to identify whether human remains are “Native American” and therefore, subject to NAGPRA;⁸⁵ second, DNA analysis might support or deny claims that human remains are “culturally affiliated” with a given tribe, and therefore subject to repatriation by that tribe under NAGPRA.⁸⁶

According to NAGPRA, tribal ancestors and their possessions can be subjected to scientific study against tribal will, but only when they are “indispensable for completion of a specific scientific study, the outcome of which would be of major benefit to the United States.”⁸⁷ This provision sets forth the only time when additional scientific study is legally allowed under NAGPRA.

Congress anticipated people and groups would push for more studies than that contemplated by NAGPRA. As a result, Congress inserted language to prevent unauthorized research of human remains. NAGPRA states that it “shall not be construed to be an authorization for, the initiation of new scientific studies . . . or other means of acquiring or preserving additional scientific information from such remains and objects.”⁸⁸ Despite this express intent within the NAGPRA, the determination of whether remains are “culturally affiliated” or “culturally unaffiliated” is at the crux of an intensive and heated debate, and has become a loophole used by scientists to block the repatriation of remains they are interested in studying. This fact is made clear by recent attempts to amend NAGPRA,⁸⁹ by the dispute over the remains in the case of *Bonnichsen v. United States, Department of the Army*,⁹⁰ and from other federal and state administrative actions involving repatriation. Most of the scientific interest is focused primarily on the oldest remains of tribal ancestors, such as the remains from Kennewick, Washington and Spirit Cave and Wizard’s Beach in Nevada.

Various generally accepted methods for determining cultural affiliation are available as a means to support repatriation efforts. For example, NAGPRA provides for “geographical, kinship . . . archaeological, anthropological, linguistic, folkloric, oral traditional, historical, or other relevant information or expert opinion” to support repatriation.⁹¹ Tribes need only

85. 25 U.S.C. § 3005(a)(4).

86. INDIGENOUS PEOPLES COUNCIL ON BIOCOLONIALISM, *supra* note 80.

87. 25 U.S.C. § 3005(b).

88. *Id.* § 3003(b)(2).

89. Douglas Preston, *The Lost Man*, NEW YORKER, June 16, 1997, at 70, 81.

90. 969 F. Supp. 628, 631 (D. Or. 1997), *aff’d*, 367 F.3d 864 (9th Cir. 2004).

91. 25 U.S.C. § 3005(a)(4).

demonstrate cultural affiliation based on “a preponderance of the evidence.”⁹² Although biology is one option, there is no requirement to use DNA analysis in support of repatriation claims.⁹³ Instead, DNA analysis has been used as a stopgap measure to block the repatriation efforts of tribes in an effort to hold remains in institutions and preserve their availability for study.

Scientists who are advocating for and using DNA analysis as a mechanism to block repatriation often fail to inform tribes and the public about the shortcomings of genetic analysis as a viable means from which to base repatriation decisions. I will discuss some of the most significant cases below. Although volumes can be written on the highly emotional and widely publicized cases below, for the sake of brevity, I will focus my discussion on the efforts by scientists to block repatriation and assert a right to study—including destructive genetic analysis—the ancestral remains of Indigenous peoples.

b. The Ancient One (Kennewick Man) Story

On July 28, 1996, two students came upon human remains on public land along the shores of the Columbia River in Kennewick, Washington.⁹⁴ The local coroner was notified, and he subsequently called a local forensic anthropologist, James Chatters, to examine the remains.⁹⁵ Chatters speculated that the skull had “Caucasoid features.”⁹⁶ “Chatters sent the left fifth metacarpal bone . . . to the University of California at Riverside” to get a radiocarbon date, and the results indicated the remains were between 9,300–9,600 years old.⁹⁷ The ancient skeleton was called the “Kennewick Man” in the media, but the area tribes call him “The Ancient One.”⁹⁸

“On September 9th, the Umatilla Indians, leading a coalition of five tribes . . . of the Columbia River Basin,” including the Colville Confederated Tribes comprised of the Umatilla, Cayuse and Walla Walla Tribes, filed a claim to repatriate The Ancient One.⁹⁹ By this time, the antiquity of the Ancient One was well known, and eight prominent scientists filed a

92. *Id.*

93. See *id.*

94. Preston, *supra* note 89, at 70.

95. *Id.*

96. *Id.*

97. *Id.* at 70, 72.

98. MARLA BIG BOY, COLVILLE TRIBAL POSITION ON THE ‘ANCIENT ONE’ (1999) (on file with author) [hereinafter TRIBAL POSITION].

99. Preston, *supra* note 89, at 72.

lawsuit in federal court to block the repatriation of the Ancient One to the Tribes, asserting a First Amendment right to study “culturally unaffiliated” remains without tribal consent.¹⁰⁰ Marla Big Boy, the Colville Tribal attorney working on the case, said, “[A]t no time did the scientists contact the tribes to work cooperatively.”¹⁰¹ When a bust was made of The Ancient One, it was no surprise that the features were considered to resemble Star Trek’s Captain Jean-Luc Picard.¹⁰² The scientists further claimed that the spear tip in his side looked like it came from France.¹⁰³

Chatters’ initial determination of “Caucasoid” was sufficient to exploit a loophole in NAGPRA wherein tribes cannot repatriate remains that are determined to be “culturally unaffiliated” to any tribe.¹⁰⁴ Under NAGPRA, remains that are determined to be culturally affiliated require the consent of the tribe for any study.¹⁰⁵ The scientists prevailed in their effort. They successfully blocked the repatriation of the Ancient One to the tribes and were granted the right to study the remains—including destructive genetic analysis.¹⁰⁶

Writing on the case, Vine Deloria Jr. noted:

I have searched the Constitution in vain to discover a word, clause or phrase that reads: “Scientists own all bones, human and otherwise, that may ever be discovered in North America.” It just isn’t there. So why do scientists and their supporters believe they have claims that absolutely must be honored in every conceivable situation, overriding even religious considerations?¹⁰⁷

In a counterpoint debate with genetic anthropologists arguing their right to study ancient DNA, Jonathan Marks and I noted:

[T]he lawsuit later brought by the anthropologists was about their perceived right to study him. But where is the existence of such a right recorded? And to the extent that scientists have ever thought that “the right to study whatever they want” is theirs, that notion is certainly abrogated when it comes into conflict with basic human rights. This is, of course, a direct result of the classic application of a “right to study” by the physical anthropologist Josef Mengele, who collected most of his best data at

100. *Bonnichsen v. United States Dep’t. of the Army*, 969 F. Supp. 628, 631, 645 (D. Or. 1997), *aff’d*, 367 F.3d 864 (9th Cir. 2004).

101. TRIBAL POSITION, *supra* note 98, at 2.

102. Preston, *supra* note 89, at 73.

103. *Id.* at 70, 76.

104. See Native American Graves Protection and Repatriation Act (NAGPRA), 25 U.S.C. § 3005(a)(4) (2006).

105. See *id.* § 3002(c)(2).

106. *Bonnichsen v. United States Dept. of the Army*, 367 F.3d 864, 882 (9th Cir. 2004).

107. Vine Deloria Jr., *Balancing Science, Culture: Do Scientists Have Rights to All Finds?*, DENVER POST, Nov. 29, 1998 at 1G.

Auschwitz.¹⁰⁸

Nearly every weekend hobbyist archaeologists and professional ones alike aligned themselves with the scientists, suggesting the body of The Ancient One “belong[ed] not to Native American tribes but to all humanity.”¹⁰⁹ Chatters went so far as to suggest that The Ancient One offered himself to be studied, explaining, “We didn’t go digging for this man. He fell out—he was actually a volunteer. I think it would be wrong to stick him back in the ground without waiting to hear the story he has to tell.”¹¹⁰

Marla Big Boy, attorney for the Confederated Colville Tribes, in an op-ed for the *Anthropology Newsletter* stated,

The use of science to disenfranchise the Native peoples of human remains for reburial is an irresponsible and unethical use of science and a violation of our human rights to rebury our dead. The type of professional arrogance of the *Bonnischen et al* plaintiffs [the scientists seeking to study the Ancient One] is also present throughout history. Since the days of contact between non-Indians and the Sovereign Nations, the scientific interests prevailed. Originally Indian Affairs was assigned under the US War Department, and Army surgeons were instructed to decapitate tribal war victims and send their heads to the Smithsonian Institute to determine by a scientific baseline that tribal peoples’ skeletal structure and brain capacity were inferior and therefore that tribal people were incapable of owning or managing land or property. What is happening today is similar to the scientific purposes of yesterday. It is an attempt by the *Bonnichsen* plaintiffs to circumvent NAGPRA for their own pecuniary and scientific interests.¹¹¹

Eventually, in the expert analysis ordered by the Court, the geneticists reported that “[n]o DNA suitable for PCR amplification could be extracted from the Kennewick samples studied. Thus, no conclusion regarding its ethnic ancestry or cultural affiliation based on DNA can be made.”¹¹² Further, experts determined that the remains are indeed culturally affiliated to the five tribes in the region, noting that:

The area surrounding the location of the discovery of the Kennewick

108. Jonathan Marks & Debra Harry, *Counterpoint: Blood-Money*, 15 EVOLUTIONARY ANTHROPOLOGY 93, 93 (2006) (footnote omitted).

109. Suzanne J. Crawford, *(Re)Constructing Bodies: Semiotic Sovereignty and the Debate over Kennewick Man*, in REPATRIATION READER: WHO OWNS AMERICAN INDIAN REMAINS? 211, 215 (Devon A. Mihesuah ed., 2000).

110. Preston, *supra* note 89, at 81.

111. Marla Big Boy, Op-Ed., *Colville Tribe on Kennewick*, ANTHROPOLOGY NEWSLETTER, May 1999.

112. David Glenn Smith et al., NAT’L PARK SERV., REPORT ON DNA TESTING RESULTS OF THE KENNEWICK HUMAN REMAINS FROM COLUMBIA PARK, KENNEWICK, WASHINGTON: CHAPTER 4: REPORT ON DNA ANALYSIS OF THE REMAINS OF “KENNEWICK MAN” FROM COLUMBIA PARK, WASHINGTON (2000), available at <http://www.nps.gov/archeology/kennewick/smith.htm>.

human remains is demonstrably an area of intergroup activity. The ethnographic and historic data specifically place the Yakama, Wanapum, Palouse, Walla Walla, Umatilla, Cayuse and Nez Perce in this area. The oral traditions place these tribes in this area since the beginning of time.¹¹³

Clearly, we have a case where science has been used to trump the human rights and religious beliefs of Indigenous peoples; not 500 years ago, but five years ago instead. In a previous article, Jonathan Marks and I noted the absurdity “that Kennewick Man died as a Native American, only to be reincarnated 9,000 years later as a European,”¹¹⁴ and yet, the myth was sufficient justification to subject The Ancient One to an intensive battery of tests, including destructive analysis and even public display,¹¹⁵ all to the horror and pain of the tribes who want to rebury their ancestor. The Ancient One continues to be disrespected by geneticists. The Genographic Project features a photograph of his skull as an insert on a promotional map included within its public participation kits (cheek swab kit, DVD, the map and other information on the project), indicating its theories of human migration with a caption that states, “[d]iscovered near Kennewick, Washington, this skull has been dated at 9,500 years old, making it one of the earliest human remains found in the Americas. Its ‘Caucasoid’ features may reflect the Central Asian origin of the first Siberians to arrive in the New World.”¹¹⁶

Despite the establishment of a federal law—NAGPRA—in 1990 that was intended to end decades of grave-robbing and desecration of the human remains by facilitating their repatriation to tribes, loopholes such as those related to cultural affiliation are exploited to effectively block repatriation, particularly of the ancient remains of most interest to scientists. Devon Mihesuah reported that currently, there are “approximately one million American Indian remains in public and private institutions” (not including remains held in private collections).¹¹⁷

113. Daniel L. Boxberger et al., NAT’L PARK SERV., CULTURAL AFFILIATION REPORT: CHAPTER 3: REVIEW OF TRADITIONAL HISTORICAL AND ETHNOGRAPHIC INFORMATION, (2000), *available at* <http://www.nps.gov/history/archeology/kennewick/boxberger.htm>.

114. Marks & Harry, *supra* note 108, at 93.

115. The Kennewick Man was publically displayed at the Burke Museum on the University of Washington campus in October, 1999.

116. Public Participation Kit Promotional Map, Genographic Project (2006) (on file with author).

117. Devon A. Mihesuah, *Introduction*, in REPATRIATION READER: WHO OWNS AMERICAN INDIAN REMAINS? 1 (Devon A. Mihesuah ed., 2000).

c. *Spirit Cave Man Story*

In 1940, archaeologists working for the Nevada State Park Commission were issued a permit by the U.S. Department of the Interior to excavate the remains of an ancient ancestor of the Fallon Paiute-Shoshone Tribe called "Spirit Cave Man."¹¹⁸ Spirit Cave Man is radiocarbon dated at around 9,400 years old.¹¹⁹ Spirit Cave Man has been held at the Nevada State Museum for over sixty-seven years.¹²⁰ In 1997, the Tribe initiated its efforts to repatriate Spirit Cave Man and three other individual ancestors taken from the same burial site.¹²¹ The Tribe's intention to repatriate its ancestor set off a flurry of opposition by the Nevada State Museum and others.

Anthropologists and a battery of consultants associated with the Nevada State Museum challenged the Tribe's repatriation efforts claiming that the Spirit Cave Man "predates Native American tribes,"¹²² that he "does not show affinity to any Amerindian sample [we used],"¹²³ and "with [a] long head, wide nose, forward face and strong chin, he resembles the Aboriginal Ainu of Japan, or other East Asians."¹²⁴ Thus, the Tribe has been put in the position of having to hire experts to build support for its case that it has the right to repatriate the remains, and to counter the false assertions of the scientists who hope to keep the remains accessible for study indefinitely.

In the study to determine cultural affiliation in accordance with NAGPRA, Dr. Stephanie Damadio, who was the National Curator of the U.S. Bureau of Land Management, led a biology study on the Spirit Cave Man.¹²⁵ A careful look at the language of the report indicates several instances where the influence of scientific interests is reflected in the find-

118. NAGPRA REVIEW COMM., MEETING MINUTES 8 (Nov. 18-20, 1999), *available at* <http://www.nps.gov/history/nagpra/REVIEW/meetings/RMS018.pdf> [hereinafter MEETING MINUTES] (discussing the testimony by Alvin Moyle, Paiute-Shoshone Tribe of the Fallon Reservation).

119. PAT BARKER ET AL., BUREAU OF LAND MANAGEMENT, DETERMINATION OF CULTURAL AFFILIATION OF ANCIENT HUMAN REMAINS FROM SPIRIT CAVE, NEVADA 12 (2000).

120. MEETING MINUTES, *supra* note 118, at 8.

121. *Id.*; Letter from Alvin Moyle to the U.S. Dept. of the Interior, Bureau of Land Management, Reno, Nev. (May 22, 1997) (claiming human remains known as "Spirit Cave Man") (on file with author).

122. Moira Breen, *Kennewick Man and Spirit Cave Man*, ALIEN CORN, Jan. 19, 2006, <http://www.aracnet.com/~dcf/pr/archives/003153.html>.

123. Sharon Begley & Andrew Murr, *The First Americans*, NEWSWEEK, Apr. 26, 1999, at 50, 54 (quoting Richard Jantz and Douglas Owsley) (alteration in original).

124. *Id.*

125. STEPHANIE M. DAMADIO, BUREAU OF LAND MANAGEMENT, WASHINGTON D.C., SPIRIT CAVE MAN: BIOLOGICAL ASPECTS 1, *available at* <http://www.blm.gov/heritage/docum/spiritnotes10.pdf>.

ings.¹²⁶

In Damadio's report, Spirit Cave Man's cranium was determined to be "Caucasoid," again an attempt to exploit the loophole in NAGPRA by calling the remains "culturally unaffiliated," as discussed in the Kennewick Man case earlier.¹²⁷ In her report, with regard to skull shape, Damadio notes that "[t]he Jantz and Owsley analysis identified the Spirit Cave Man cranium closest to 'Norse' and 'Ainu.'"¹²⁸ She then explains that "[i]t should be noted that the probability for Norse was 0.00084, with Ainu an even lower probability."¹²⁹ It must be noted that Jantz and Owsley are also among the plaintiffs in the Kennewick Man lawsuit.¹³⁰

Damadio reports that the hair analysis resulted in varying conclusions, casting (the intended) doubt on the cultural affiliation of Spirit Cave Man, including findings that suggest the hair was Caucasian, Asian, Mongoloid, Northern Asian, or Native American:

Lahren reports that the "... density and distribution of the pigment granules, ... a moderate shaft diameter with minimal variation, and an oval cross-sectional shape ... are consistent with hair derived from ...a Caucasian individual."

... DiZinno ... observed "... numerous dark reddish-brown, Asian origin head hairs".

... Deedrick found "all of the hairs submitted exhibit microscopic characteristics consistent with originating from an individual of Asian (Mongoloid) ancestry" ...

Goodman and Martin observing only gross morphology note, "we now judge the hair to be medium to dark brown and straight. In other words, the hair is exactly the color and form [sic that] is most common in Northern Asian or a Native American."¹³¹

It is no wonder that Damadio's report concludes:

Given the current state of scientific technology, methodology and theoretical framework, there is no biological information available at this time which would allow the assignment of Spirit Cave Man to an affiliation with a particular tribe. There is no available biological information which clearly supports cultural continuity with contemporary North American Indians. The biological information does not indicate that

126. *Id. passim*.

127. *Id.* at 12; See Native American Graves Protection and Repatriation Act (NAGPRA), 25 U.S.C. § 3005(a)(4) (2006).

128. DAMADIO, *supra* note 125, at 11.

129. *Id.*

130. *Bonnichsen v. United States Dep't of the Army*, 969 F. Supp. 628, 628 (D. Or. 1997), *aff'd*, 367 F.3d 864 (9th Cir. 2004).

131. DAMADIO, *supra* note 125, at 13 (citations omitted).

there is, "a relationship of shared group identity which can reasonably be traced historically or prehistorically between members of the present-day Indian tribe . . . and an identifiable early group," as required by NAGPRA. No biological findings to date indicate by a "preponderance of the evidence" that there is an "affiliation" of Spirit Cave Man to a particular tribe.¹³²

And then, going beyond the scope of a biology examination, she further declares:

Current and future advances in genetics, biochemical and metric analyses may hold the key to modern human origins and the peopling of the New World. Paleoamerican materials address a period of human evolution about which there is still a great deal unknown. . . . The data derived from the Spirit Cave Man could provide answers to the characterizations of migrational interactions of migrations in both the Old and New World.

Many Americans, African Americans, Hispanic Americans and European Americans, have Native American ancestry. Therefore, all American communities have a right to the knowledge these remains can provide. The antiquity and rarity of Spirit Cave and other Paleoamerican remains and artifacts are critically important to the biological history of contemporary *Homo Sapiens*. These facts make Spirit Cave Man and other Paleoamerican remains National Patrimony.¹³³

In 1999, the Fallon Paiute-Shoshone Tribe presented its case to the primary oversight body of NAGPRA, called the NAGPRA Review Committee.¹³⁴ After, a series of presentations were made by the Tribe and other interested parties, the Review Committee issued its findings on April 10, 2002 in a 6–1 decision:

1. The review committee does not believe that the Nevada State Office has given fair and objective consideration and assessment of all the available information and evidence in this case; and

2. The review committee finds that the preponderance of the evidence indicates a relationship of shared group identity which can be reasonably traced between the present-day Fallon Paiute-Shoshone Tribe and the human remains and associated funerary objects from Spirit Cave in Nevada.¹³⁵

Based on these findings, the Review Committee recommended that the responsible federal agency, the Bureau of Land Management (BLM), "repatriate the Spirit Cave human remains and associated funerary objects

132. *Id.* at 17 (citation omitted).

133. *Id.* at 18.

134. MEETING MINUTES, *supra* note 118, at 8.

135. Native American Graves Protection and Repatriation Review Committee Findings and Recommendations Regarding Human Remains and Associated Funerary Objects from Spirit Cave in Nevada, 67 Fed. Reg. 17463, 17463 (Apr. 10, 2002).

to the Fallon Paiute-Shoshone Tribe.”¹³⁶ Unfortunately, the Review Committee recommendations are not binding, another gaping hole in the legislation.

On July 26, 2000, the BLM issued its determination on cultural affiliation, taking into account numerous studies, including the biology study above, and issued this finding:

Based on a review of the evidence from the tribe, as well as the evidence gathered from other sources, the BLM has concluded that the preponderance of the available evidence demonstrates that the human remains from Spirit Cave are appropriately considered to be unaffiliated with the Northern Paiute, i.e., the remains predate contemporary Northern Paiute tribes and cannot reasonably be culturally affiliated with any of them. Thus, the BLM has determined that the remains from Spirit Cave are unaffiliated with any modern individual, tribe, or other group and are therefore culturally unidentified.¹³⁷

The Fallon Paiute-Shoshone Tribe has had to initiate legal proceedings in federal court. According to the Tribe’s Vice-Chairwoman, Rochanne Downs, the court has ordered the U.S. BLM to make a new determination on cultural affiliation with a November 30, 2007 deadline for the submission of new comments by interested parties.¹³⁸ She says, “What happens then is anyone’s guess. Do we go back to court, or back to the Review Committee if they come back with a negative determination?”¹³⁹ Rochanne says, “I’ve worked on this case for the past 10 years. I made a promise to our ancestor to bring him home. Our Tribe has had to invest significant resources that could have gone to meet social needs. It’s really a justice issue.”¹⁴⁰

We do not know when the Fallon Paiute-Shoshone Tribe will find justice for its ancient ancestor, but when it does, we will all celebrate its courage and tenacity in fighting to protect the sanctity of this ancient ancestor. As Western Shoshone spiritual elders tells us:

Without respect and without culture we have nothing. The Indian people were told to forget about the past, but we can’t forget about the past. One of our responsibilities is to protect our ancestors, protect their graves. We can’t just go out there and dig them out and move them someplace else. That’s not according to our ways. We don’t have ceremonies for that. It makes a lot of our elders, our elders back home, angry

136. *Id.*

137. BARKER ET AL., *supra* note 119, at 66.

138. Telephone Interview with Rochanne Downs, Vice-Chairwoman, Fallon Paiute-Shoshone Tribe, in Fallon, NV (Nov. 25, 2007).

139. *Id.*

140. *Id.*

because things like this are happening all over no matter where you go.¹⁴¹

d. Wizard's Beach Man Story

In an appeal to the Nevada legislature for funding support, the Nevada State Museum (NSM) indicates that it has 100 prehistoric human burials in its facility, including five of the oldest human skeletons in the "New World."¹⁴² One of those remains is an ancient one called Wizard's Beach Man, taken in 1978 along with funerary items from the shores of *Kooyooee Pah*¹⁴³ (Pyramid Lake), an area entirely within the exterior boundaries of the Pyramid Lake Paiute Tribe Reservation where I am from. There is no written proof of tribal consent for removal of the skeletal and associated burial items from the Reservation or for the DNA testing that has been conducted.

Given the location of the burial, it seems logical that the Pyramid Lake Paiute Tribe has an automatic right to repatriate our ancient one. However, the scientists associated with the NSM claim these remains "represent . . . people who probably are not related to the Paiutes and might not be ancestors of any Indian tribe."¹⁴⁴

To further analyze the Wizard's Beach Man story, I interviewed Norman Harry, who has served in different positions including Chairman on our Tribal Council for over twenty years. Harry believes these scientific assertions are malicious and inconsistent with the intent of NAGPRA.¹⁴⁵

We did not have a written language. Ours is an oral history so it puts Tribes at a disadvantage. Because the scientific community is saying, "prove it." How can you prove that? You can't? The intent of the law was good but it's not working.¹⁴⁶

This is a clear attempt to undermine the aboriginal rights, including the right to repatriate, of the Great Basin Tribes by rewriting history. The revisionist history serves a purpose, as the NSM document further explains:

141. CHRISTOPHER SEWALL, *DIGGING HOLES IN THE SPIRIT: GOLD MINING AND THE SURVIVAL OF THE WESTERN SHOSHONE NATION* 31 (1999) (quoting Corbin Harney, Western Shoshone).

142. Amy Dansie, *International Implications of the Impact of Repatriation in the Nevada Museums*, SAA BULLETIN, May 1999, available at http://www.saa.org/Portals/0/SAA/publications/SAA_bulletin/17-3/saa14.html.

143. Kooyooee Pah is the name of Pyramid Lake in the Paiute language.

144. Frank Mullen Jr., *Ancient Bones Are Center of Contention*, RENO GAZETTE-J., Feb. 8, 1998, at 1C.

145. Interview with Norman Harry, former Chairman, Paiute Tribal Council, in Nixon, Nev. (Nov. 29, 2007).

146. *Id.*

[T]hey [Native Americans] assume, like most anthropologists until very recently, that any human older than European contact in the new world is by definition a Native American. New findings have challenged that assumption, with ancient remains expressing significant traits more often found in Caucasian (White) skeletons than in Indian skeletons. . . . The Museum is seeking the opportunity to learn as much as possible from these ancient humans before they are reburied under federal law.¹⁴⁷

The NSM cites a NAGPRA provision on scientific study as the justification to “regard all human remains in their custody as subjects for study.”¹⁴⁸ The NAGPRA provision in question states:

If the lineal descendant, Indian tribe, or Native Hawaiian organization requests the return of culturally affiliated Native American cultural items, the Federal agency or museum shall expeditiously return such items unless such items are *indispensable for completion of a specific scientific study, the outcome of which would be of major benefit to the United States*. Such items shall be returned by no later than 90 days after the date on which the scientific study is completed.¹⁴⁹

This provision sets forth the only time when additional scientific study is legally allowed under NAGPRA.¹⁵⁰ Whether the measurement, carbon dating, and crushing of our ancestors’ bones is a matter of major benefit to the United States is debatable. Harry says “you’d have to have a heart” in order to realize that these acts are desecrations.¹⁵¹ A fair-minded and objective reader of this section of NAGPRA, taking into account the intent of the law as human rights legislation, would conclude that this section would *prohibit* any study, unless it were a matter of the utmost importance to the United States. And a fair-minded and good-hearted person would find no possible situation of such great importance to the government that would necessitate destructive analysis on the ancestors of peoples who want to peacefully lay them back to rest. Harry remarked during my interview with him that

[genetic research] has been focused specifically on Tribes. If this were such a great tool in determining the history of mankind they’d be digging up their own people and their own graveyards and saying, “okay lets see what happened back then” . . . And its outcome is like one grain of sand on a beach, yet they take it like fact. They’re trying to rewrite history by

147. A. Dansie & Donald Tuohy, Prehistoric Human Burial Study: Overview, Issues and Proposals (1997) (unpublished report, on file with the Nevada State Museum Department of Anthropology).

148. *Id.*

149. Native American Graves Protection and Repatriation Act (NAGPRA), 25 U.S.C. § 3005(b) (2006) (emphasis added).

150. INDIGENOUS PEOPLES COUNCIL ON BIOCOLONIALISM, *supra* note 80.

151. Interview with Norman Harry, *supra* note 145.

saying our Paiute people have only been here for 1600 years.¹⁵²

I am not sure if Congress could see the heartless motives of the scientists at the time NAGPRA was passed, but Congress certainly did anticipate that scientific interests would push for more studies than those contemplated by the Act. Thus, Congress inserted language in NAGPRA to prevent unauthorized research of human remains, stating, “[T]his chapter shall not be construed to be an authorization for, the initiation of new scientific studies . . . or other means of acquiring or preserving additional scientific information from such remains and objects.”¹⁵³

It comes as no surprise then that our Ancestor found at Wizard’s Beach is determined to be “culturally unaffiliated” at this time. Clearly, the ultimate goal of a small but powerful, well-funded, and influential sector of the scientific community is to secure the freedom to conduct scientific study on these so-called “culturally unaffiliated” human remains, and this effort is focused primarily on the oldest remains of our tribal ancestors. Harry believes the scientists have other motives: “They [the scientists intervening in repatriation] secure millions of dollars to do destructive analysis testing, and yet it’s only being done on our people.”¹⁵⁴ As long as these ancient remains are shrouded in a fabricated mythology of ancient—Caucasian and other—peoples who predated the Indigenous peoples of the Great Basin region, the scientists will be free to molest and desecrate these ancient ancestors. The NSM says, “If they are to be repatriated, they must be repatriated to their actual descendants, the most affiliated Tribe, or else it should be called something else.”¹⁵⁵

The NSM asserts that its research will result in “data important to understanding the original people of the New World. Therefore, the NSM will continue to study the human remains in possession of the Museum until the issues of affiliation and repatriation are resolved. . . . Information important to all Americans is emerging from these studies.”¹⁵⁶

Carbon-dating can be useful to establish a general timeframe of when a person lived, and thus, be used to designate remains that are 300–500 years old as definitively Native American. Remains dating more recent than that could conceivably be Native American or post-contact settlers. If necessary, at that point a process of determining “cultural affiliation” may

152. *Id.*

153. 25 U.S.C. § 3003(b)(2).

154. Interview with Norman Harry, *supra* note 145.

155. Dansie & Touhy, *supra* note 147.

156. *Id.*

commence in order to determine whether the remains are Native. Many Native Americans, including myself, also refer to the carbon-dating results not to “prove,” but to supplement and complement our own knowledge about how long we have been here. But when I listen to the logic of scientists, or those speaking in the interest of science, I see that they are attempting to set up a system where any remains that are carbon-dated more than 2000–3000 years old will no longer be considered Native American. Somehow, the older the remains are, the more “Caucasoid” or “European” they become. I can imagine bones bleaching white over time due to exposure to the elements, but I did not know that they changed racial or cultural identity.

Given this adamancy by the scientists, it is clear that the government intends to keep the ancient ancestors on its cold museum shelves. It is no wonder that tribes are experiencing such difficulty in repatriating their ancestors. Harry says,

If we look at what is being done to our people, and our deceased, it becomes a human rights issue. Even our deceased have a right to be returned to the earth in a respectful way, as they had been put away in the beginning. But to be excavated to have things that were sacred to them being taken to different part of the world has disrupted their spiritual journey.¹⁵⁷

It is necessary to examine the afterlife of the Kennewick Man case because it has grave implications for my peoples’ struggle to return Wizard’s Beach Man and the struggle of the Fallon Paiute-Shoshone Tribe to repatriate its ancient one. Harry explained that the Pyramid Lake Tribal Council made a conscious decision, based on the political climate, to wait out the ultra-conservative Bush Administration and the outcome of the Kennewick Man case.¹⁵⁸ Since the 2004 Ninth Circuit Court of Appeals’ decision allowing scientific study on the remains, tribes have pushed for an amendment to NAGPRA that would essentially create a legal presumption that all ancient remains found in the country are Native American.¹⁵⁹ Attempts at passage of such an amendment have failed so far.

The latest bill to amend NAGPRA was introduced in the US Senate in late September 2007.¹⁶⁰ These amendments were quickly contested by Friends of America’s Past, a Portland-based organization that has sided

157. Interview with Norman Harry, *supra* note 145.

158. *Id.*

159. Annette Cary, *Bill Could Untie Bones*, TRI-CITY HERALD (Kennewick, Wash.), Oct. 4, 2007, at A1, available at <http://www.tri-cityherald.com/1211/story/58541.html>.

160. S. 2087, 110th Cong. (2007).

with the scientific establishment in the debate.¹⁶¹ Cleone Hawkinson, a founding member of Friends of America's Past finds that:

The new definition would assume that any remains found would belong to only federally recognized tribes. . . . That includes remains from small bands of people who died out and left no ancestors, and remains of indigenous ancestors to modern-day Latinos, including those who died just a couple hundred years ago.¹⁶²

Hawkinson claims that this "narrows down and distorts history."¹⁶³ Friends of America's Past has further added that "[u]nless this amendment is withdrawn, public access to the factual understanding of the nation's prehistory shifts to the exclusive control of federally recognized American Indians."¹⁶⁴ Who exactly is rewriting history here?

Within a month of the pro-tribal Senate amendment, Representative Doc Hastings (Republican from Washington State) introduced a counter-amendment bill in the House of Representatives.¹⁶⁵ Hastings said, "I hope the introduction of my legislation will help bring balance to what is being done on the other side of the Capitol, and that scientific inquiry is not extinguished through the quiet acts of the U.S. Senate."¹⁶⁶ Hastings' proposed bill "spell[s] out that Congress intended NAGPRA only to 'apply to human remains or other cultural items that have a special, significant and substantial relationship to presently existing Native Americans' and that the relationship could not be based on geography alone."¹⁶⁷

In the three stories of the ancient ones described above, an obvious and weighty piece of evidence that the tribes assert to make their claim for repatriation is that the remains were found within their aboriginal territory. Unlike Kennewick Man and Spirit Cave Man, which were found on federal lands, (Army Corp of Engineers and BLM). Wizard's Beach Man was found clearly on the Pyramid Lake Paiute Tribe Reservation. Harry believes that, "since he (Wizard's Beach Man) was found on the Tribe's reservation, there should be a presumption of tribal jurisdiction, not federal, and this should translate to mean automatic repatriation with "no questions asked; no genetic studies conducted."¹⁶⁸

161. Cary, *supra* note 159, at A2.

162. *Id.*

163. *Id.*

164. *Id.*

165. Annette Cary, *Hastings' Bill Would Protect Study of Bones*, TRI-CITY HERALD (Kennewick, Wash.), Nov. 1, 2007, at A1, available at <http://www.tri-cityherald.com/1211/story/58376.html>.

166. *Id.* at A2.

167. *Id.*

168. Interview with Norman Harry, *supra* note 145.

Kennewick Man, Spirit Cave Man, and Wizard's Beach Man are not just three unrelated stories. Indeed they are actually intimately interrelated and collectively tell a larger story beyond the Umatilla, Paiute, or Shoshone Tribes who seek to repatriate their ancestors. Although our arrows easily, and justifiably, fly towards the scientists who assert an unfettered right to study our ancestors, we must dig deeper and examine the U.S. Government's far more devious Indigenous rights divestiture plan. The political and legal implications of these ancient ones' collective story is broad and far reaching.

Once again, science in the hands of government serves a colonialist agenda, an agenda that certainly is a "major benefit to the United States."¹⁶⁹ A determination of "culturally unaffiliated" not only extinguishes a right under NAGPRA to repatriate, it is also a direct attack on all of our rights as Indigenous peoples. If Native Americans are "proven" not to be the original inhabitants of the United States, then there are no governmental obligations to recognize our Indigenous rights; no obligations to recognize our sovereignty and related jurisdiction over our reservations (which has already been eroded away congressional act after congressional act and court case upon court case); no obligations to recognize our prior and paramount rights to water; no obligations to consult our tribal governments when the Federal Government act may pose an impact to tribal lands or resources. No legal obligation to uphold these rights would certainly be a major benefit to the United States. It is the same colonial agenda of genocide, this time facilitated by so-called "scientific evidence." In the past the Government shot us down in cold blood or they wrapped us in small pox-laden blankets, forcefully relocated us, and terminated our sovereign status, but now they try to erase our history with one fell swoop of the scientific pen.

As the stories above demonstrate, there has been a lot of effort by scientists to convince tribes that they can determine the cultural affiliation of human remains through DNA analysis. However, any inference that DNA analysis is useful in such determinations is based on both a misunderstanding of the concept of cultural affiliation and a false belief that the science of genetics can provide concrete answers as to native identity.¹⁷⁰

The ability of genetics to provide conclusive proof of ancestry is very

169. 25 U.S.C. § 3005(b).

170. Jonathan Marks & Brett Lee Shelton, *Genetic "Markers"—Not a Valid Test of Native Identity*, INDIGENOUS PEOPLES COUNCIL ON BIOCOLONIALISM, http://www.ipcb.org/publications/briefing_papers/files/identity.html (last visited May 5, 2009).

limited. Jonathan Marks, genetic anthropologist, explains why:

Both females and males inherit their mitochondrial DNA (mtDNA) only from their mother. This line of biological inheritance, therefore, stops with each male. That means that, if you think of your 4 great-grandmothers, you and all your brothers and sisters have inherited your mtDNA only from your maternal grandmother's mother. Your other 3 great-grandmothers and your 4 great-grandfathers have contributed none of your mtDNA. If you are female, you and your sisters will, in turn, transmit that great-grandmother's mtDNA to all your children, but your brothers won't transmit it to their children. In other words, your mtDNA is identical to that of your mother's mother's mother, but does not constitute a biological line of descent from your other 7 great-grandparents. If that great-grandmother happened to have the genetic variations that have been labeled as either A, B, C, D or X, then by having the same mtDNA yourself, you will have inherited a "Native American" mtDNA marker.¹⁷¹

The same would hold true if analyzing the paternally Y-chromosome, which is passed from father to son.

Marks further explains that it is easy to get false-negative and false-positive results using these tests because

there is a very high chance of someone having a significant amount of their ancestry being Native American, and yet appearing to be non-Native according to the test. All it takes is one non-Native person located in the proper position in a person's ancestry. A woman's mother's grandmother could be non-Indian [or one who simply didn't carry these markers], and all her 7 other great grandparents Indian, and the test will still show the woman as non-Indian.¹⁷²

There are other variables to consider. Scientists have not tested all native people, so they do not know for sure that only Native Americans have the markers which have been identified as Native American. A false negative could arise "if some Native American people simply do not have one or more of the 'Native American' markers."¹⁷³ Further, genetic sequencing and analysis represents a first approximation and does not take into account the fact that as cells divide there can be genetic changes over time. Marks also explains that:

Some of the haplotypes attributed to Native Americans are also found in people from other parts of the world. A, B, C, and D are found in North Asia, and X is found in southern Europe and Turkey. In fact, the principal marker of haplotype B is called the "9 base pair deletion," and is found in some Japanese and almost all Samoans. Could they then be

171. *Id.*

172. *Id.*

173. *Id.*

classified as genetically Native American? These tests cannot establish with certainty that . . . someone's mother's mother's mother was Native American, they can at best establish a certain probability that this was the case.

. . . .

Another issue is the widespread belief that genetics can help determine specific tribal affinities of either living or ancient people. This is quite simply false. Neighboring and distant tribes have long-standing complex relationships involving intermarriage, raiding, adoption, splitting, and joining. These social historical forces insure that there cannot be any clear-cut genetic variants differentiating all the members of one tribe from those of nearby tribes. At most, one can identify slight differences in the proportions of certain genetic variations in each group, but those do not permit specific individuals to be assigned to particular groups.¹⁷⁴

In addition to not providing much conclusive evidence of biological relationships, DNA testing simply cannot help in the determination of cultural affiliation. Cultural affiliation is a connection to a particular form of civilization involving the beliefs, customs, arts, and institutions of a society at a given time. Clearly, cultural affiliation does not include a biological component.

II. COMMON ISSUES

A. *Patenting and Commercialization of Human Genes*

Indigenous peoples have experienced the appropriation and patenting or attempted patenting of their genetic material. Indeed, there have been several well-known cases of attempts to patent cell lines derived from Indigenous peoples in the past. This is demonstrated in three stories of Indigenous peoples the Guyami of Panama, the Hagahai of Papua New Guinea, and the Melanese of the Solomon Islands.

1. Guyami Story

In August 1993, while researching data from the American Type Culture Collection, a U.S. Government operated gene bank, the Canadian-based non-governmental organization Rural Advancement Foundation International (RAFI) discovered that the U.S. Government had applied for U.S. and world patents on the cell line of a twenty-six year old Guyami

174. *Id.*

woman from Panama.¹⁷⁵ Her cell line was of interest because some Guyami people carry a unique virus, and their antibodies might have been useful in AIDS and leukemia research.

The Guyami patent drew swift opposition from the Guyami General Congress, the World Council of Indigenous Peoples, and a growing list of Indigenous peoples and non-governmental organizations opposed to human gene patents, all of whom called for the withdrawal of the patent application.¹⁷⁶ Under the mounting global opposition, the United States withdrew its patent application in November 1993.¹⁷⁷

2. Hagahai Story

In early January 1994 RAFI learned from Swiss colleagues that there were two more patent claims by the U.S. Government over the genetic material of Indigenous peoples.¹⁷⁸ The first patent application, filed by the U.S. Department of Health and Human Services and the National Institutes of Health (NIH), claimed a human T-cell line of a Hagahai man from Papua New Guinea.¹⁷⁹ In 1995, the patent was granted, and later, in 1996, it was abandoned. The Hagahai peoples of Papua New Guinea were the subjects of a patent application filed by the NIH and an anthropologist named Carol Jenkins who was doing research on the Hagahai.

According to Alphonse Kambu, this was not the first time Indigenous peoples of Papua New Guinea were exploited by research, referring to the “discovery of a variant form of Cretzfeldt-Jacob Disease or *kuru*, which earned Carlton Gajdusek a Nobel Prize.”¹⁸⁰

The Hagahai cell line was available to the public at the American Type Culture Collection as ATCC Number: CRL-10528 Organism: *Homo Sapiens* (human) at \$216 for several years; however, it is no longer offered at the ATCC website.¹⁸¹

175. *The Patenting of Human Genetic Material*. RAFI COMMUNIQUE, Jan.–Feb. 1994, at 7, available at http://www.etcgroup.org/en/materials/publications.html?pub_id=492 (click “download PDF”).

176. *Id.* at 7–8.

177. *Id.* at 8.

178. *Id.*

179. *Id.*; U.S. Patent No. 5,397,696 col.33 l.18 (filed Aug. 12, 1991).

180. Alphonse Kambu, *Lessons from Omissions in the Hagahai Patent Case*, in *PACIFIC GENES & LIFE PATENTS* 138, 138 (Aroha Te Pareake Mead & Steven Ratuva eds., 2007).

181. The Hagahai cell is no longer available from the Coriell catalog. However, it had been available for the past several years.

3. Melanese Story

The second patent application was filed in the name of the U.S. Department of Commerce for the human T-cell line of a 40-year-old woman and a 58-year-old man from the Solomon Islands.¹⁸² The government of the Solomon Islands, in the Pacific, protested the patent application for the Indigenous Solomon Islanders' DNA, and the U.S. Government responded that "[u]nder our laws, as well as those of many other countries, subject matter relating to human cells is patentable and there is no provision for considerations relating to the source of the cells that may be the subject of a patent application."¹⁸³

There is currently discussion in the WTO, WIPO, and the Convention on Biological Diversity to develop certificates of origin for non-human genetic material as a mechanism to ensure source countries receive fair and equitable benefit-sharing from the exploitation of resources. It remains to be seen whether a similar scheme will be devised for human genetic material.

The late Hopi geneticist Dr. Frank Dukepoo, in his paper on Native American perspectives regarding the patenting of human genes, found that for many of the Indigenous peoples he surveyed, the principle of giving and sharing permeates the thinking of those who participate in biomedical research, and they will go to great lengths to help others.¹⁸⁴ However, many Indigenous peoples draw the line when it comes to the commercialization of human genes. Dr. Dukepoo asked one elderly traditional woman afflicted with a debilitating genetic condition if she would approve of someone taking a genetic sample from her, claiming ownership through patent, and then possibly making some money from her DNA.¹⁸⁵ The woman replied, "It would be all right if they took the sample. But as far as owning it, no, I don't think that's right."¹⁸⁶ Dr. Dukepoo asked, "Why?" The woman replied, "Because they can't own a part of my body. I don't even own my body. It was given for me to use and it belongs to the Great Spirit."¹⁸⁷

182. *The Patenting of Human Genetic Material*, *supra* note 175, at 9.

183. Kara H. Ching, Note, *Indigenous Self-Determination in an Age of Genetic Patenting: Recognizing an Emerging Human Rights Norm*, 66 *FORDHAM L. REV.* 687, 700-01 (1997) (citing Letter from former Dep't of Commerce Secretary Ron Brown to Solomon Islands United Nations Ambassador Rex Horoi (Mar. 3, 1994)).

184. Frank, C. Dukepoo, *Native American Perspectives on Genetic Patenting*, in *PERSPECTIVES ON GENETIC PATENTING* 75, 80 (Audrey R. Chapman ed., 1999).

185. *Id.*

186. *Id.*

187. *Id.*

B. Notions of Disappearing Peoples, Genetic Homogeneity, and the Survival of Indigenous Cultures

Both the HGDP and the Genographic Project are based on the notion of disappearing peoples.¹⁸⁸ Describing the urgency to collect DNA from “so-called indigenous people,” Dr. Wells of the HGDP says, “we’re racing against the clock. The stories carried in the DNA of indigenous people are being subsumed into the cultural melting pot.”¹⁸⁹

Dr. Wells has said that it is important to do this research “before the geographic and cultural context [of Indigenous peoples’ DNA] are lost in the melting pot.”¹⁹⁰ Principal financier of the Project, Ted Waitt of Gateway Computers, has stated, “while genetic clues are still present and likely most pure in their DNA, the snapshot this research is attempting to take will not be present forever.”¹⁹¹ A *Newsweek* article reports that “[t]he project’s overarching goal is to collect DNA from Indigenous populations worldwide . . . and to do it fast before whole populations die out and leave their ancestral homelands.”¹⁹²

These projects stress an urgency to collect Indigenous peoples’ DNA before we have vanished forever. The intent to collect and preserve our DNA without any concern for our continued survival is a notion many Indigenous peoples find offensive. George Annas, Professor of Medical Ethics at the Massachusetts Institute of Technology, referring to the HGDP stated, “We’re taking from them their DNA, which we now consider like gold. It’s even worse than standard colonialism and exploitation because we are taking the one thing that we value. And after we take that we have no real interest in whether they live or die.”¹⁹³

188. In the Genomics article that first announced the Human Genome Diversity Project in 1991, lead HGDP scientists asserted the following:

The populations that can tell us the most about our evolutionary past are those which have been isolated for some time, are likely to be linguistically and culturally distinct, and are often surrounded by geographical barriers. . . . Isolated human populations contain much more informative genetic records than more recent, urban ones. Such human populations are being rapidly merged with their neighbors, however, destroying irrevocably the information needed to reconstruct our evolutionary history.

JONATHAN MARKS, WHAT IT MEANS TO BE 98% CHIMPANZEE 203–04 (2002).

189. SPENCER WELLS, DEEP ANCESTRY: INSIDE THE GENOGRAPHIC PROJECT 4 (2006).

190. María Amparo Lasso, *Gene Study Puts Indians on Guard*, TIERRAMÉRICA, <http://tierramerica.net/2005/0423/iarticulo.shtml> (last visited Feb. 28, 2009).

191. *Our World* (Voice of America radio broadcast Apr. 15, 2005) (transcript available at <http://www.voanews.com/english/archive/2005-04/Copy-of-Our-World-Transcript-2005-04-16.cfm>).

192. Kalb, *supra* note 48, at 46.

193. Videotape: *The Gene Hunters* (Films for the Humanities & Sciences 1995) (on file with the Charles E. Shain Library, Connecticut College).

We also see population geneticists structure their projects around the notion that Indigenous peoples have lived in genetic isolation, or as the HGDP terms, “isolates of human history.” For example, Dr. Wells describes the characteristics of his ideal subjects for the Genographic Project:

Ideally they would be living in the same place as their ancestors did centuries ago. They should have been relatively isolated from immigration from surrounding groups who have moved into the region recently. They also should retain some of their ancestors’ way of life, be it language, marriage patterns, or other cultural attributes. In other words, what we want are *indigenous* people.¹⁹⁴

Jonathan Marks explains that “ethnic groups are categories of human invention, not given by nature.”¹⁹⁵ Marks has been a vocal critic of using the false constructions of race and culture in genetic research, stating, “the worst mistake you can make in human biology is to confuse constructed categories with natural ones.”¹⁹⁶ There has always been an admixture of human populations throughout time. Sociologist Barbara Katz-Rothman comments, “[t]he one thing we do know about people is that when populations of them interact, crossing each other’s paths, little mixed babies are a sure product. So static isolation is probably not a good model for what happened to us as a species.”¹⁹⁷ The combined notions of homogenous gene pools resulting from supposedly complete geographical isolation and disappearing peoples are incorrect, misleading, and disingenuous.

Ironically, the Genographic Project claims it wants to promote cultural diversity, yet acknowledges its findings may contradict Indigenous peoples knowledge of themselves. In fact, its informed consent form states: “It is possible that some of the findings that result from this study may contradict an oral, written, or other tradition held by you or by members of your group.”¹⁹⁸ Indigenous knowledge is the foundation of cultural diversity, and this project may undermine these diverse worldviews with a so-called “scientific truth.” In actuality, the findings of human history genetic research will produce data that cannot, itself, be validated in any scientific

194. WELLS, *supra* note 189, at 45.

195. MARKS, *supra* note 188, at 202.

196. *Id.*

197. BARBARA KATZ ROTHMAN, *THE BOOK OF LIFE: A PERSONAL AND ETHICAL GUIDE TO RACE, NORMALITY, AND THE IMPLICATIONS OF THE HUMAN GENOME PROJECT* 104 (Beacon Press 2001) (1998).

198. NAT’L GEOGRAPHIC SOC’Y SOC. & BEHAVIORAL SCI., *CONSENT FORM—NORTH AMERICA 2* (2005) (attachment to UNIV. OF PA. SOC. AND BEHAVIORAL SCI. INST. REVIEW BOARD, OFFICE OF REGULATORY AFFAIRS, *TECHNICAL SUMMARY OF PROJECT PROTOCOL & INFORMED CONSENT FORM, THE GENOGRAPHIC PROJECT* (2005) [hereinafter *CONSENT FORM*], available at http://www.ipcb.org/pdf_files/GP_protocol.pdf).

manner. The genetic data can only, at best, be statistical in nature and inconclusive scientifically. Despite the speculative nature of genetic research on human histories, these findings could be used politically to undermine “indigeness” or “aboriginality” of Indigenous peoples and our rights as the original inhabitants of our territories.

Indigenous cultures will survive as long as Indigenous peoples exist. We are not artifacts that should be preserved in genetic museums. To be clear, saving genes does not constitute saving cultures or people.

C. *Gene Banks*

The samples collected from Indigenous peoples ultimately end up in a gene bank of some sort, whether it is in a researcher’s private laboratory collection or held in some publicly accessible gene bank. These genetic collections or gene banks may be held by military, federal, academic, or private facilities for use in future medical or non-medical research.¹⁹⁹ In addition, many institutions maintain collections of DNA specifically from identifiable populations, including Indigenous peoples.²⁰⁰ The DNA samples and any data acquired in relation to the subject’s cultural or familial background can be maintained indefinitely. The blood samples can also be “immortalized” for future study utilizing a technique of cell transformation which keeps cells viable for several years and capable of generating unlimited amounts of DNA available for research. Walter Bodmer, former president of the Human Genome Organization and proponent of the HGDP, describes the process for immortalizing Indigenous peoples’ DNA as follows:

Once a blood sample is sent to a centre, it is placed in a centrifuge and its B lymphocyte cells are removed. These are then infected with Epstein Barr virus, the causative agent of glandular fever. This particular virus triggers a process by which the B lymphocytes start to divide uncontrollably, the end result being an eternal supply of cells which, of course, contain the DNA of the blood donor. These cell lines become a permanent source of his or her genes and, repeated over and over again for all the world’s different peoples, can be used to establish a living museum of human diversity, a repository of our genetic variability which can then be probed by the latest techniques of molecular biology. Creating this molecular Noah’s Ark will be one of the most significant acts of

199. Rebecca Skloot, *Taking the Least of You: The Tissue-Industrial Complex*, N.Y. TIMES MAG., Apr. 16, 2006, at 38, available at <http://www.nytimes.com/2006/04/16/magazine/16tissue.html>.

200. For instance, Principle Investigator of the HGDP, Dr. Kenneth Kidd, proudly shows his collection of Indigenous peoples’ cell lines at Yale University in the film *The Gene Hunters*. *The Gene Hunters*, *supra* note 193.

the Human Genome Project.²⁰¹

In Bodmer's description, we see an allusion to Christian theology and the dehumanizing notion of banking Indigenous peoples' DNA in a museum.

The HGDP maintains its cell lines at the *Centre d'Étude Polymorphisme Humain* in Paris, France.²⁰² In the United States, the Coriell Institute for Medical Research in Camden, New Jersey maintains the Coriell Cell Repositories. The Coriell Cell Repositories maintains population-based samples in its Human Populations Collection.²⁰³ The Coriell Institute was established by the NIH's Institute for General Medical Sciences and serves as a primary federal storage facility in the United States.²⁰⁴ These samples are available to researchers at any institution, and access is presumably based on some form of informed consent given at the time of collection, or prior to a new use. In the case of identifiable populations, such as Indigenous peoples, Coriell implements a special policy that requires collectors to consult and gain group consent, in addition to individual consent, for the storage and use of samples.²⁰⁵

Some consent forms, as is the case of the Genographic Project, require the donor to provide blanket consent to allow his or her samples to be used for future research.²⁰⁶ This situation leaves Indigenous peoples in a position of having to trust the researchers to serve as guardians of their DNA, derived data, genealogies, and oral histories—a relationship reminiscent of the colonizer “protecting” the colonized peoples.

There is a trend to consider human genetic material and data in the public domain. The International Human Genome Mapping Consortium published the draft sequence of the human genome, stating the information “has been immediately and freely released to the world, with no restrictions on its use or redistribution.”²⁰⁷ Taking the lead from the international ge-

201. Walter Bodmer & Robin McKie, *The Book of Man: The Human Genome Project and the Quest to Discover Our Genetic Heritage* 174 (Scribner 1995) (1994).

202. Howard M. Cann et al., *A Human Genome Diversity Cell Line Panel*, 296 *SCIENCE* 261, 261 (2002).

203. Coriell Institute for Medical Research, NIGMS Human Genetic Cell Repository, <http://ccr.coriell.org/Sections/BrowseCatalog/Populations.aspx?PgId=4> (last visited Oct. 1, 2009).

204. Coriell Institute for Medical Research, About Coriell, <http://www.coriell.org/index.php/content/view/110/234> (last visited Apr. 30, 2009).

205. CORIELL INST. FOR MED. RESEARCH, POLICY FOR THE RESPONSIBLE COLLECTION, STORAGE, AND RESEARCH USE OF SAMPLES FROM NAMED POPULATIONS FOR THE NIGMS HUMAN CELL REPOSITORY (2004), <http://ccr.coriell.org/Sections/Support/NIGMS/CollPolicy.aspx?PgId=220>.

206. CONSENT FORM, *supra* note 198, at 2.

207. Press Release, Whitehead Inst. for Biomed. Research, International Human Genome Mapping Consortium Publishes Physical Map of the Human Genome (Feb. 12, 2001), available at http://www.wi.mit.edu/news/archives/2001/e1_0212b.html.

netic research collaborations, one author suggests that

Putting the Hawaiian genetic material into the public domain seems to be the approach that is most harmonious with the tenets of traditional Hawaiian culture. Indeed, this is the approach the International HapMap Project intends to take, which will place its results into the public domain and make them accessible on the internet.²⁰⁸

Any attempt to unilaterally place Indigenous peoples' DNA in the public domain would undermine the internationally recognized right of Indigenous peoples to free, prior, and informed consent,²⁰⁹ and the right to control any use of their DNA.²¹⁰

D. Informed Consent

A common ethical standard in research involving human subjects is that informed consent must be obtained from individuals who participate in research—that is, researchers are required to obtain consent from their subjects after the subjects have been fully informed about the research, including the risks and the benefits. The subjects have a right to decide whether to participate, including the right to know what is necessary in order to make a good decision. In federally regulated research, the law states that:

[N]o investigator may involve a human being as a subject in research . . . unless the investigator has obtained the legally effective informed consent of the subject or the subject's legally authorized representative. An investigator shall seek such consent only under circumstances that provide the prospective subject or the representative sufficient opportunity to consider whether or not to participate and that minimize the possibility of coercion or undue influence. The information that is given to the subject or the representative shall be in language understandable to the subject or the representative.²¹¹

In other words, "Individual persons have the ethical and legal right not to be research subjects without their voluntary, competent, informed, and understanding consent."²¹² Federal policy is limited to research conducted or supported by the U.S. Government, and to certain types of research regulated by the Government, such as testing of experimental new drugs, for

208. Lindsey Singeo, Note, *The Patentability of the Native Hawaiian Genome*, 33 AM. J.L. & MED. 119, 128 (2007).

209. United Nations Declaration on the Rights of Indigenous Peoples, G.A. Res. 61/295 art. 32, U.N. Doc. A/RES/61/295 (Sep. 13, 2007).

210. *Id.* art. 31.

211. 45 C.F.R. § 46.116 (2008).

212. George J. Annas, Editorial, *Rules for Research on Human Genetic Variation - Lessons from Iceland*, 342 NEW ENG. J. MED. 1830, 1831 (2000).

example. The requirement for informed consent applies to individuals, not collective groups. For this reason, the HGDP proposed a model ethical protocol that included a requirement for group consent.²¹³ The notion of group consent is considered important because when research that is focused on, and impacts, an identifiable group, that group should be afforded an opportunity to consent with regard to its participation.

The definition of what constitutes informed consent is subjective. For example, under the Genographic Project's North American research protocol, researchers "anticipate that the time required to enroll research participants, explain the project, obtain informed consent, ask and answer questions, and take the blood or cheek swab sample will take 20 minutes per person."²¹⁴ If an Indigenous person consents to participate in the Genographic Project, the informed consent form requires them to provide blanket consent to have their samples available for future human migration studies.²¹⁵

The participation of Indigenous peoples in the consent process must consist of receiving additional consent for the taking of blood or other biological samples. There is a growing body of international law that recognizes the collective right of Indigenous peoples to free, prior, and informed consent as well as consultation in development projects that affect them.²¹⁶ However, a policy to require the free, prior, and informed consent in human genetic research is still emerging. Most notably, the United Nations Education, Science and Cultural Organization's (UNESCO) Declaration on the Protection of the Human Genome makes mention of group consent where applicable:

No research or its applications concerning the human genome, in particular in the fields of biology, genetics and medicine, should prevail over respect for the human rights, fundamental freedoms and human dignity of individuals or, where applicable, of groups of people.²¹⁷

213. 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, 1443 (1997).

214. UNIV. OF PA. SOC. AND BEHAVIORAL SCIS. INST. REVIEW BD., OFFICE OF REGULATORY AFFAIRS, TECHNICAL SUMMARY OF PROJECT PROTOCOL & INFORMED CONSENT FORM, THE GENOGRAPHIC PROJECT 9 (2005) [hereinafter TECHNICAL SUMMARY], available at http://www.ipcb.org/pdf_files/GP_protocol.pdf.

215. CONSENT FORM, *supra* note 198, at 2.

216. See, e.g., G.A. Res. 61/295, *supra* note 209, arts. 10, 11, 19, 28; U.N. Econ. & Soc. Council [ECOSOC], Permanent Forum on Indigenous Issues, *International Workshop on Methodologies Regarding Free Prior and Informed Consent and Indigenous Peoples*, ¶ 51, U.N. Doc. E/C.19/2005/3 (Feb. 17, 2005).

217. U.N. Educ., Sci. & Cultural Org. [UNESCO], *Universal Declaration on the Human Genome and Human Rights*, art. 10 (1997), available at http://portal.unesco.org/en/ev.phpURL_ID=

Further, the minimum standard of informed consent should not be borne by Indigenous peoples. The burden of proof should be on the researchers to ensure the highest standards of transparency and ethical conduct in human subject research.

E. Repatriation of Genetic Material

Indigenous peoples have often run into serious difficulty in efforts to repatriate their own DNA once it has left their control. For example, it took the Nuu-chah-nulth twenty years to finally regain control of the blood samples that they consented to for arthritis research at the UBC, but which ended up at Oxford University in England in an institutional transfer that they never consented to.²¹⁸ The Yanomami of Brazil have yet to successfully repatriate their DNA—taken in the 1960s—and they certainly could not have foreseen that the samples would still be in use decades later.²¹⁹ Although the Nuu-chah-nulth have successfully repatriated their genetic samples, Dr. Spencer Wells is still applying the data gained from them, which he likely had access to while he was studying at Oxford.²²⁰

With little means to hold researchers accountable, Indigenous peoples are often left with little or no recourse once their DNA leaves their territories. There is no forum for their claims and no mechanism for repatriation, and perhaps most importantly, no interest by geneticists to return parts of their coveted and exotic DNA collections. After all, they depend on continued access to samples and data. This is why the Genographic Project seeks to create the largest database of genetic information from the samples they collect. They further propose to keep all the genetic material collected in the regional centers; although, the Genographic Project has made this decision largely to assuage anticipated fears of the United States Government hoarding the global gene collection.

One Native attorney warns that tribes need to understand the potential pitfalls of genetic research, including immortalization of cells and the circulation of samples among colleagues, because these common practices make the repatriation of body specimens difficult.²²¹ Tribes must also keep

13177&URL_O=DO_TOPIC&URL_SECTION=201.html.

218. Wiwchar, *supra* note 28, at 1, 3.

219. David Glenn, *Science BC (Before Consent)*, CHRON. OF HIGHER EDUC., Mar. 3, 2006, at A16.

220. Wiwchar, *supra* note 28, at 1, 3.

221. NAT'L INST. OF GEN. MED. SCIS. & NAT'L HUMAN GENOME RESEARCH INST., AMERICAN INDIAN AND ALASKA NATIVE GENETICS RESEARCH POLICY FORMATION MEETING SUMMARY MEETING REPORT 10 (2001), available at http://www.nigms.nih.gov/News/Reports/grpf_report.htm [hereinafter NIGMS/NHGRI Report].

in mind that once genetic materials are provided, in most cases, the samples will leave the reservation for university, government, or corporate laboratories. It is therefore essential for tribes to lay the ground rules for use of their peoples' genetic material before the research project commences. Once these samples leave the reservation, they leave the jurisdiction of the tribe, unless otherwise agreed to in advance.

F. Benefits of Genetic Research

There is an assumption that scientific research is beneficial to human kind. But closer scrutiny reveals that the real beneficiaries in scientific research are the intellectual property rights holders, who ultimately will benefit financially from any products brought to market. It is critical to understand genetic research as a part of the market economy. It takes significant investment on the front-end of research and development to reap rewards from genetic products in the marketplace. And with genetics, new gene "discoveries," gene sequences, cell lines, and any products developed from them are a "genetic shot in the dark."²²² But, the payoffs are lucrative enough, and there is certainly good opportunity for the basic research to be funded.²²³ The resulting belief is that we should donate for the good of humankind, benefit to the public, and science in the private interest.. The problem is well described by Jonathan Marks in his latest book:

[T]he crux of the issue for geneticists at the millennium: Who decides what genetic problems are important? Traditionally, it has been the scientists defining the research questions, with indigenous peoples as passive pincushions.²²⁴

G. Sacredness of the Human Body

Many Indigenous peoples have identified a cultural and spiritual relationship with genetic material when examined through a cultural lens. For example, Maori academic and activist Aroha Mead, of Ngati Awa and Ngati Porou tribal lineage, explains that "the human gene is genealogy. A physical gene is imbued with a life spirit handed down from the ancestors, contributed to each successive generation, and passed on to future genera-

222. This phrase was used by Michael Pollan to describe genetic engineering, implying it is not as an exact science as scientists would have us believe. It seems an appropriate use of the phrase here as well.

223. SHELDON KRIMSKY, *SCIENCE IN THE PRIVATE INTEREST: HAS THE LURE OF PROFITS CORRUPTED BIOMEDICAL RESEARCH?* 79 (2003).

224. MARKS, *supra* note 188, at 217.

tions.”²²⁵ Indigenous Solomon Islander Ruth Liloqula explains that “[t]he substance of social identity is the relationship with one’s relatives through blood.”²²⁶ Therefore, her people traditionally place great value in knowing and protecting their genealogy and body parts, whether blood, hair, nails, saliva, or placenta.²²⁷ Indigenous peoples have a relationship with DNA akin to that which we have with our ancestors—one of reverence, respect, and responsibility.

Several Indigenous peoples recognize an inherent sacredness in DNA. For example, Navajo elders have expressed that “the threats of genetics are based on the compromising of the sacred.”²²⁸ The elders stress that genetic research is not the same as other types of research because it deals with an individual’s body parts. The body specimens that are currently used to extract deoxyribonucleic acid (DNA)—e.g., blood, hair, and saliva—are very sacred to the Navajo.²²⁹ Similarly, the National Congress of American Indians (NCAI), the oldest and largest national organization comprising representatives of all the American Indian tribal governments in the United States, took a stand in 1993 against the Human Genome Diversity Project.²³⁰ The NCAI resolution states, in part, “the taking of blood, hair and tissue samples is an affront to the religious beliefs, cultural values, and sensitivities of many indigenous peoples.”²³¹ Dr. Paul Reynolds of Auckland University urged Maori not to participate in the project explaining:

This type of research is colonization as usual. Indigenous people will be saying we already have our stories about our origins, so we don’t need a scientific rationale to justify our origins. And of course the collection of DNA through blood samples goes against our view of the body as tapu, or sacred, which also leads on to the misuse of the body and body parts by some researchers.²³²

Human genes represent a composite of one’s ancestral lineage, which is further shaped and influenced by the environmental and social conditions

225. Aroha Te Pareake Mead, *Genealogy, Sacredness, and the Commodities Market*, CULTURAL SURVIVAL Q., Summer 1996, at 46–47.

226. Ruth Liloqula, *Value of Life: Saving Genes Versus Saving Indigenous Peoples*, CULTURAL SURVIVAL Q. Summer 1996, at 42–43.

227. *Id.*

228. NIGMS/NHGRI REPORT, *supra* note 221, at 8 (summarizing Marla Jasperse’s explanation of her elders’ concerns regarding genetic research).

229. *Id.*

230. World Council of Indigenous Peoples, Resolution Condemning the Human Genome Diversity Project, Res. No. WCIP/VII/GUA/1993/2 (Dec. 10, 1993), available at http://www.ipcb.org/resolutions/htmls/res_wcip.html; see also e.g., MARKS, *supra* note 188, at 198–212; REARDON, *supra* note 42.

231. World Council of Indigenous Peoples, *supra* note 230.

232. Simon Collins, *Maori Alarm at Gene Project*, N.Z.HERALD.CO.NZ, April 24, 2005, http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=10122157 (quoting Dr. Paul Reynolds).

of the human experience. One's children and unborn generations are the rightful heirs to this ancestral lineage.

Native Hawaiians have issued the Paoakalani Declaration which states, "Kanaka Maoli human genetic material is sacred and inalienable."²³³

The days of objectifying human beings in research should have ended with the Nuremburg Trials, but many of these same intractable problems are visible in the trials and tribulations of Indigenous peoples in a biocolonial world. These experiences have generated a collective body of knowledge about genetics, based on flawed science, inadequate ethics, and the unjust application of such research.

Indigenous peoples have been adamant in rejection of human population-based genetic research projects. The early 1990s initiatives, such as the proposed HGDP, which specifically targeted Indigenous populations for the collection of blood samples, drew widespread opposition. The World Council of Indigenous peoples, after hearing a presentation by Henry Greely, the Chair of the HGDP Ethics Committee, issued a declaration that stated, "[w]e resolve to categorically reject and condemn the human genome diversity project as it applies to our rights, lives and dignity."²³⁴

A protocol concerning human genetic research contained in the Treaty for a Life Forms Patent-Free Pacific states, "Indigenous peoples of the Pacific do not support the objectives of the Human Genome Diversity Project or any project which seeks to collect, store, immortalize, research or commercialize the genetic materials of the indigenous peoples of the Pacific."²³⁵ Aboriginal peoples issued a position paper on the HGDP and became the first group to nickname it as "The Vampire Project." The paper stated "The Vampire Project is legalized theft. The Vampire scientists are planning to take and to own what belongs to indigenous people. . . . We must make sure that our people are not exploited once more by corporations, governments, and their scientists."²³⁶ A briefing held in Kuna Yala, Panama in 1997 for twenty-five Indigenous leaders from throughout Central and South America resulted in the Ukupseni Declaration on the Human

233. PALAPALA KULIKE OKA'AHA PONO PAOAKALANI DECLARATION ¶ 20 (2003), available at <http://papaolalokahi.org/coconut/resources/pdf/PaoakalaniDeclaration05.pdf>.

234. World Council of Indigenous Peoples, *supra* note 230.

235. *Protocol Concerning Human Genetic Research in the Pacific*, in PACIFIC GENES & LIFE PATENTS, *supra* note 180, at 212 art. 3.

236. INDIGENOUS PEOPLES COUNCIL ON BIOCOLONIALISM, INDIGENOUS PEOPLES OPPOSITION TO THE HGDP ¶ 7, http://www.ipcb.org/resolutions/htmls/summary_indig_opp.html (last visited Apr. 30, 2009) (quoting CENT. AUSTRALIAN ABORIGINAL CONGRESS, POSITION PAPER ON THE HGD "VAMPIRE" PROJECT (1993)).

Genome Diversity Project in November 1997. The Ukupseni Declaration stated, “[t]hat this research and other research projects on Indigenous peoples genome go against human life and, in particular, violate the genetic integrity of Indigenous Peoples and their values,” and “[t]he process of genetic collection, based on deception and exploitation of poverty and marginalization, violates fundamental human rights and collective rights, often with the consent of governments.”²³⁷

In response to patenting Indigenous peoples’ DNA, a 1995 Declaration of Indigenous Peoples of the Western Hemisphere called for “an immediate moratorium on collections and/or patenting of genetic materials from indigenous persons and communities by any scientific project, health organization, governments, independent agencies, or individual researchers” and expressed “solidarity to all those who are . . . seeking the repatriation of genetic materials already taken.”²³⁸ The Declaration further stated, “[w]e oppose the patenting of all natural genetic materials. We hold that life cannot be bought, owned, sold, discovered or patented, even in its smallest form”²³⁹ Similarly, the Palapala Kulike O’Ka’Aha Pono Paoakalani Declaration, issued in October 2003 by Kanaka Maoli, the Indigenous peoples of the Hawaiian Archipelago, states, “Kanaka Maoli human genetic material is sacred and inalienable. Therefore, we support a moratorium on patenting, licensing, sale or transfer of our human genetic material.”²⁴⁰

When it comes to genetic research, what is lacking is a legal, political, social, and ethical framework that guarantees the protection of the most fundamental human rights of Indigenous peoples amid this rush to collect diverse human genetic resources. Without safeguards that ensure Indigenous peoples understand the full implications of their participation in genetic research, understand the potential for secondary uses of their genetic samples and data, and receive measures to ensure prior, fully informed group and individual consent, many of these projects will continue to exploit the world’s most vulnerable peoples. Indigenous peoples need to be

237. INDIGENOUS PEOPLES COUNCIL ON BIOCOLONIALISM, UKUPSENI DECLARATION, KUNA YALA ON THE HUMAN GENOME DIVERSITY PROJECT (HGDP) ¶¶ a–b (1997), *available at* http://www.ipcb.org/resolutions/htmls/dec_ukupseni.html.

238. INDIGENOUS PEOPLES COUNCIL ON BIOCOLONIALISM, DECLARATION OF INDIGENOUS PEOPLES OF THE WESTERN HEMISPHERE REGARDING THE HUMAN GENOME DIVERSITY PROJECT para. 19, 22 (1995), *available at* http://www.ipcb.org/resolutions/htmls/dec_phx.html.

239. *Id.* para. 13.

240. PALAPALA KULIKE OKA’AHA PONO PAOAKALANI DECLARATION ¶ 20 (2003), *available at* <http://papaolalokahi.org/coconut/resources/pdf/PaoakalaniDeclaration05.pdf>.

active participants, not passive subjects, in these processes to ensure their perspectives and interests are represented and protected.

While the field of biotechnology moves forward at lightning speed, public policies to protect the rights of human subjects in research fail to keep pace. Policies which address the unique political, legal, and cultural status of tribes are still emerging, as researchers who recognize the complications of conducting ethical research in distinct socio-political-cultural populations struggle with the issues raised by genetic research. The vast potential for genetic theft, exploitation, commercialization, and human rights abuses to occur in the field is widely recognized by both scientific researchers and Indigenous peoples alike. As a result, a number of bio-ethical protocols have been proposed at all levels of policy (WHO, UNESCO, NIH, and others) that attempt to set standards regarding the ethical conduct of genetic research involving Indigenous populations. Until firm policies are established, the late Dr. Frank Dukepoo, one of my most treasured mentors and dearest of friends, recommends the following:

Those who come to the discussion table must do so with open hands, open minds and clear hearts—there can be no hidden agendas. Concerned parties must be honest and respectful of one another. Mutual trust should be a common goal.

Before these discussions transpire, there is the question of what to do with current research. Here the Indian response is loud and clear. STOP! Declare a moratorium until the issues are resolved. What about tribes or communities who wish not to participate in biomedical/biotechnical research? The answer: LEAVE THEM ALONE. What about those who are uneducated or uninformed? EDUCATE AND INFORM THEM. And what about those who wish to participate in biogenetic/biomedical research? Answer: DO IT RIGHT. Be honest, treat them with respect, show them you are trustworthy. Adhere to the research protocols that are being designed by and for Indians.²⁴¹

III. ESTABLISHING PROTECTIONS FOR INDIGENOUS PEOPLES

When it comes to interaction with external entities, including non-Indigenous researchers, Indigenous peoples need to consider mechanisms that ensure equity, justice, and respect for the community or group as equal and principal partners. Tribal governments, particularly in the United States, must realize that they, as sovereign nations, have the ability to control and direct research that impacts their community and environment. A handful of tribes have adopted codes and/or protocols to govern human

241. Dukepoo, *supra* note 184, at 85.

subject research within their territories.

For example, the Navajo Nation and Cherokee Nation have established institutional review boards responsible for evaluating and regulating human subject research involving tribal members. The Navajo Nation Human Research Code requires that prior to any human research within the Tribe's territorial jurisdiction, a researcher must apply for and receive a permit from a research review board.²⁴² The Code established the Navajo Nation Human Research Review Board, which has the power to review and approve or disapprove research proposals.²⁴³ The Code requires a researcher to agree to the civil jurisdiction of the Navajo Nation with respect to both the research to be undertaken and any publications arising from such research.²⁴⁴ The Navajo Code is particularly strong in protecting the Tribe's intellectual property in the research and the inevitable publications that are generated. For example, it is Navajo policy that "[r]esearch information and data generated by and about Navajo individuals, communities, [and] culture represent inalienable intellectual properties of the Navajo people."²⁴⁵ The Navajo Nation has mandated that all data and research subject to the Code are the property of the Nation.²⁴⁶ The Research Review Board is vested with power to review and approve all presentation materials and manuscripts, including theses, dissertations, and abstracts, prior to publication.²⁴⁷

In September 2003, the IPCB released the Indigenous Research Protection Act (IRPA),²⁴⁸ a model ordinance to help American Indian tribes protect their peoples and resources from unauthorized research;²⁴⁹ to reduce the adverse affects of research on the Tribal community;²⁵⁰ to ensure that researchers recognize tribal control and ownership of all information generated or produced by the research;²⁵¹ and finally to establish a statutory basis for the governance of research within their jurisdictions.²⁵² Na-

242. NAVAJO NATION HUMAN RESEARCH CODE §§ 12, 14 (1995), *available at* <http://www.nnhrb.navajo.org/pdf/NNHumanResearchCode.pdf>.

243. *Id.* § 10(a).

244. *Id.* § 14.

245. *Id.* § 3(c).

246. *Id.* § 5(c).

247. *Id.* § 10(b).

248. INDIGENOUS PEOPLES COUNCIL ON BIOCOLONIALISM, INDIGENOUS RESEARCH PROTECTION ACT (2008), *available at* <http://www.ipcb.org/publications/policy/files/irpa.html>.

249. *Id.* § 2.1(a).

250. *Id.* § 2.1(b).

251. *Id.* § 2.1(c).

252. *Id.* § 2.1(d).

tive American attorneys who serve on IPCB's staff and Board of Directors developed IRPA by incorporating elements of existing tribal codes, model codes, and ethical guidelines.²⁵³ Updated in 2008, the revised IRPA builds upon IPCB's previous work by expanding the provisions that specifically address issues raised by biotechnology, particularly the protection of genetic material and Indigenous knowledge.²⁵⁴ IRPA contains provisions that are probably not included in most existing tribal legal codes on cultural resource protection, but that need to be considered in the area of genetic research, including access to and protection of both non-human and human genetic material.

The IRPA encourages the development of a tribally established Research Review Committee: a voluntary (or non-voluntary) body that is charged with review, oversight, and liaison between the researcher(s) and the tribal community and governing body.²⁵⁵ The Committee would develop processes and procedures that ensure protection of both the individual members and the collective tribal rights and interests in research.²⁵⁶ This would include procedures to ensure informed consent, to protect privacy, to govern the extraction, use, and disposal of bodily or other biological materials, to restrict any unauthorized secondary research, to protect tribal intellectual property over the research findings, and to ensure benefit-sharing arrangements when appropriately generated from the research.²⁵⁷ The IRPA also includes model guidelines for the establishment of the Committee.²⁵⁸

When tribes are fully involved in the review, design, and implementation of research that meets their needs, the research is likely to result in greater benefits. This changes the paradigm from Indigenous peoples being simply research subjects to being active partners in research with control over the research process.²⁵⁹

253. See, e.g., AKWESASNE TASK FORCE ON THE ENVIRONMENT (ATFE), PROTOCOL FOR REVIEW OF ENVIRONMENTAL AND SCIENTIFIC RESEARCH PROPOSALS (1996), available at http://www.northnet.org/atfe/webdocs/atfe_protocol.pdf; AMERICAN INDIAN LAW CENTER, MODEL TRIBAL RESEARCH CODE (1999), available at <http://www.pre.ethics.gc.ca/english/pdf/mdl-code1.pdf>; CAN. INST. OF HEALTH RESEARCH, GUIDELINES FOR HEALTH RESEARCH INVOLVING ABORIGINAL PEOPLES (2007), available at <http://www.cihir-irsc.gc.ca/e/29134.html>.

254. INDIGENOUS PEOPLES COUNCIL ON BIOCOLONIALISM, INDIGENOUS RESEARCH PROTECTION ACT §§ 1.3–1.5, (2008), available at <http://www.ipcb.org/publications/policy/files/irpa.html>.

255. *Id.* § 4.2.

256. *Id.*

257. *Id.*

258. *Id.* § 5.

259. For a more detailed discussion about the IRPA, see Debra Harry & Le'a Malia Kanehe, *Asserting Tribal Sovereignty Over Cultural Property: Moving Towards Protection of Genetic Material*

Tribes not only have the right to protect the communal and individual interests of their community: indeed, it is their responsibility to do so. Tribes that have legal jurisdiction can establish regulatory frameworks for the research and protection of cultural property as an assertion of sovereignty. Indigenous peoples, by being creative and assertive in their regulatory schemes, will ensure that multiple levels of protection are established to protect their biological and cultural property in a manner consistent with their own cultural values, traditions, and customs.