

1997

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### Recommended Citation

Kara H. Ching, *Indigenous Self-Determination in an Age of Genetic Patenting: Recognizing an Emerging Human Rights Norm*, 66 Fordham L. Rev. 687 (1997).

Available at: <https://ir.lawnet.fordham.edu/flr/vol66/iss2/15>

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## NOTE

### INDIGENOUS SELF-DETERMINATION IN AN AGE OF GENETIC PATENTING: RECOGNIZING AN EMERGING HUMAN RIGHTS NORM

*Kara H. Ching*

#### INTRODUCTION

Genes and the information they contain are fundamental building blocks of a people's identity. Genetic research on groups of people occasionally results in lucrative biotechnology patents. For example, approximately half of the inhabitants of the South Atlantic island of Tristan da Cunha suffer from asthma.<sup>1</sup> Researchers from the San Diego biotechnology firm Sequana Therapeutics collected genetic material from this group and located a genetic mutation.<sup>2</sup> The German company Boehringer Ingelheim funded the research and bought this ground-breaking information for \$70 million.<sup>3</sup> From this information, Boehringer Ingelheim plans to develop a treatment to effectively alleviate asthma symptoms.<sup>4</sup> Researchers have recently targeted indigenous peoples<sup>5</sup> for genetic study because their heightened isolation

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1. *See Asthma-Related Gene Found in Study on Small Island, Firm Says*, L.A. Times, May 21, 1997, at A18 [hereinafter *Asthma-Related Gene*]. The inhabitants of this island are not indigenous, but the example is meant to illustrate that genetic research involving relatively isolated groups can prove to be lucrative.

2. *Id.*

3. *Id.*; see Paul Salopek, *Genes Offer Sampling of Hope and Fear*, Chi. Trib., Apr. 28, 1997, at 8.

4. *Asthma-Related Gene*, *supra* note 1.

5. Defining indigenous groups is difficult. See Russel Lawrence Barsh, *Indigenous Peoples and the UN Commission on Human Rights: A Case of the Immovable Object and the Irresistible Force*, 18 Hum. Rts. Q. 782, 791-94 (1996). The following is one definition from the U.N. Sub-Commission on Prevention of Discrimination and Protection of Minorities:

Indigenous communities, peoples and nations are those which, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing in those territories, or parts of them. They form at present non-dominant sectors of society and are determined to preserve, develop and transmit to future generations their ancestral territories, and their ethnic identity, as the basis of their continued existence as peoples, in accordance with their own cultural patterns, social institutions and legal systems.

Special Rapporteur José R. Martínez Cobo, Study of the Problem of Discrimination Against Indigenous Populations, at 29, U.N. Doc. E/CN.4/Sub.2/1986/7/Add.4, U.N. Sales No. E.86.XIV.3 (1987); see also, Julian Burger, Gaia Atlas of First Peoples 20 (1990) ("Although indigenous people vary widely in their customs, culture, and impact on the land, all consider the Earth a Parent and revere it accordingly. 'Mother Earth' is the center of the universe, the core of their culture, the origin of their identity as a people."); Jose P. Kastrup, *The Internationalization of Indigenous Rights from*

may have resulted in unique genetic traits of increased resistance or susceptibility to disease.<sup>6</sup>

There are many competing interests in the arena of sampling and patenting of indigenous peoples' genetic material. Genetic research has the potential to yield diagnostic tools and cures for diseases, and many people suffering from or predisposed to these diseases stand to benefit. Other potential beneficiaries include scientists, pharmaceutical companies, and the larger health industry, all of which could profit from a successful product. In addition, anthropologists, geneticists, and indigenous peoples could learn more about the migratory history of indigenous tribes through genetic research.<sup>7</sup>

Notwithstanding these potential benefits, indigenous peoples have concerns about the procurement and use of their genetic materials.<sup>8</sup> Many are worried about researchers obtaining genetic samples without the informed consent of their subjects.<sup>9</sup> Some of these peoples' religious or philosophic beliefs do not permit the patenting of life.<sup>10</sup> No avenues exist for these peoples to enjoin the patenting of their genetic material. No mechanisms beyond private contract currently ensure that the indigenous donors will be adequately compensated, or compensated at all, for their contribution. Moreover, many indigenous people may never have access to medical advances based on their own genetic material because they do not live near medical facilities.

The following hypotheticals demonstrate some of the potential controversies. Suppose that a private U.S.-based company (the "Company") sent researchers (the "Researchers") into three indigenous communities. Samples were gathered from the first group ("Group One") by a physician at a health clinic in the course of unrelated routine treatment with no remuneration, where the subjects were unaware that their samples would be used in research. The physician was working with Researchers who were interested in this indigenous

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*the Environmental and Human Rights Perspective*, 32 *Tex. Int'l L.J.* 97, 99-102 (1997) (comparing international and U.S. definitions of indigenous peoples).

For an overview of indigenous rights issues, see S. James Anaya, *Indigenous Peoples in International Law* (1996) [hereinafter *Indigenous Peoples in International Law*], S. James Anaya, *Indigenous Rights Norms in Contemporary International Law*, 8 *Ariz. J. Int'l & Comp. L.* 1 (1991), and Steven C. Perkins, *Indigenous Peoples and International Organizations: Issues and Responses*, 23 *Int'l J. Legal Info.* 217 (1995).

6. See Salopek, *supra* note 3, at 8; see also L.L. Cavalli-Sforza et al., *Call for a Worldwide Survey of Human Genetic Diversity: A Vanishing Opportunity for the Human Genome Project*, 11 *Genomics* 490 (1991) ("Isolated human populations contain much more informative genetic records than more recent, urban ones.").

7. See, e.g., Ann Gibbons, *The Peopling of the Americas*, *Science*, Oct. 4, 1996, at 31 (describing new theories of the prehistoric migration of people from Asia to North and South America that are based, in part, on genetic research of indigenous peoples).

8. See *infra* Parts I.C. & I.D.

9. See, e.g., *infra* note 43 and accompanying text.

10. See, e.g., *infra* note 66 and accompanying text.

group and gave the samples to them. Samples were also taken from Groups Two and Three. Unlike with Group One, however, the Researchers told the second group that their blood samples would be used in research in exchange for some nominal consideration. The Researchers stated, without further explanation, that there was a remote chance that they would develop and patent a product derived from the samples. Group Three, in contrast, was given an in-depth explanation of genetics and patenting. The researchers obtained permission from the traditional leaders and each individual, agreeing that a fixed share of any resulting profits would be returned to the group.

Researchers were surprised to find that members of all three tribes possessed a genetic makeup that was critical in the development of potentially lucrative patentable products. Without informing the tribes or individual donees, the Company applied for, and the United States granted, patents for the products. Some time later, members of the tribes became aware of the patents and notified both the Company and the United States that they objected to the patents. There were no individual dissenters to the Groups' decisions to object. Group One members complained because they had not been informed or given their permission for that use of their genetic material, nor had they received remuneration. Members of Group Two advanced ethical objections because genetic research violated their belief that people should not tamper with nature. Group Three members dissented because they believed they were inadequately compensated under the agreement.

This Note explores how the law can help indigenous peoples obtain meaningful control of their genetic material. Part I will briefly discuss the background of genetics, life patents, and indigenous groups. Part II sets out the domestic common law and international human rights law and demonstrates that neither currently provide adequate protection for indigenous peoples. Part III considers the human right of self-determination in the context of indigenous research and patenting, and illustrates that an emerging international norm recognizes an indigenous people's right to control their genetic material. Part IV argues that Congress should pass legislation to adequately meet the human rights needs of indigenous peoples generated by the rapid advancement of biotechnology. This Note concludes that congressional action to protect indigenous peoples is consistent with domestic and international law, and is a natural advancement of human rights and responsible state action.

#### PART I. BACKGROUND

Genetics is intriguing because genes hold answers to some of life's mysteries. Scientists study human genes hoping to discover some insight into genetic diseases that will alleviate human suffering. Some genetic research has aroused interest in the genes of indigenous peo-

ples who have been isolated and unexposed to a larger gene pool. Recent genetic research of indigenous people, however, has raised several serious concerns about its appropriateness. This part begins by providing a brief overview of genetic research and life patents, and continues by identifying competing interests and illustrating some of the concerns surrounding indigenous genetic research with specific examples.

### A. Genetic Research

Genes contain the well-hidden secrets of human frailties and strengths.<sup>11</sup> The human genome is genetic information encoded in deoxyribonucleic acid ("DNA") which is found tightly coiled in the chromosomes of each human cell.<sup>12</sup> The human genome consists of a long sequence of nucleotide bases which contain approximately three billion base pairs.<sup>13</sup> Some stretches of the nucleotides form the 50,000-100,000 genes found in human cells, while the rest are "junk" DNA, not currently expressed in humans.<sup>14</sup> Genes are stretches of DNA that contain the code to produce a protein.<sup>15</sup> Proteins are the material of cellular structure and they also determine most chemical reactions in the body.<sup>16</sup>

The scientific community has found many applications for genetic information. For example, scientists value the development of cell lines because these lines enable them to conduct controlled studies.<sup>17</sup> Researchers seek to develop diagnostic tools to detect genetic defects or predisposition to genetic diseases that could lead to medical intervention.<sup>18</sup> Another goal of genetic research is protein production,

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11. See Leon Jaroff, *The Gene Hunt*, Time, Mar. 20, 1989, at 62, 63, 67 (quoting former head of the National Institute of Health, James Watson, in regard to human genome mapping: "We can have at our disposal the ultimate tool for understanding ourselves at the molecular level. . . . We used to think our fate was in our stars. Now we know, in large measure, our fate is in our genes.").

12. DNA is a molecule that forms a double helix of four base nucleotides that pair off: adenine with thymine and guanine with cytosine. See Robert Cook-Deegan, *The Gene Wars: Science, Politics, and the Human Genome* 19 (1994) (describing the double helix as a spiral staircase). For much more in-depth and technical explanations of DNA, genes, and cells, see Bruce Alberts et al., *Molecular Biology of the Cell* (3d ed. 1994), and James D. Watson et al., *Molecular Biology of the Gene* (4th ed. 1987).

13. Thomas F. Lee, *Gene Future: The Promise and Perils of the New Biology* 14 (1993).

14. Some geneticists believe that these long stretches of DNA may have had functions in the past that have since been obviated by evolution. *Id.*

15. Cook-Deegan, *supra* note 12, at 19.

16. *Id.*

17. Cell lines aid genetic study by fostering a stable environment for research because the same cells can be infinitely reproduced. See Jean de Vellis, *Ownership of Cell Lines*, 65 S. Cal. L. Rev. 697 (1991) (explaining the development and use of cell lines).

18. See, e.g., *Visible Genetics Receives United States Patents for p53 and RB1 Cancer Gene Tests*, Biotech Pat. News, Sept. 1, 1996, available in 1996 WL 8691838

which is a vital method of replacing necessary proteins when genetic diseases inhibit their normal production.<sup>19</sup> Ultimately, researchers seek to develop cures and preventatives for the many diseases that have a genetic basis, ranging from cancer to diabetes, heart disease to sickle cell anemia.<sup>20</sup>

To achieve these goals, scientists have set out to map the entire human genome.<sup>21</sup> The goal of mapping is to sequence all of the nucleotide base pairs and determine the location of genes.<sup>22</sup> Because genes are at the root of many diseases, scientists want to identify links between genetic markers and the location of a disease-producing gene on chromosomes.<sup>23</sup> Mapping and determining the genetic sequence of a critical gene could make possible a diagnosis or identification of a predisposition, cure, or preventative measure.<sup>24</sup> The Human Genome Project ("Genome Project"), a worldwide network of genetic researchers, has developed a systematic plan to coordinate the complete mapping of the human genome.<sup>25</sup>

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(describing test kits that provide fast, inexpensive detection of genetic mutations associated with cancer, which leads to early intervention).

19. See, e.g., Lawrence M. Fischer, *American Home Products Will Buy the Rest of Genetics Institute*, N.Y. Times, Dec. 18, 1996, at D4 ("Genetics Institute . . . is best known for a genetically engineered replacement therapy, sold as Recombinate, for the blood-clotting protein that hemophiliacs lack.").

20. See, e.g., Lawrence M. Fischer, *Bottling the Stuff of Dreams: Gains in Gene Therapy Encourage the Industry*, N.Y. Times, June 1, 1995, at D1 (examining gene therapy companies that are working to correct genetic defects that cause disease by generating proteins that stimulate the immune system or replace damaged genes).

21. Scientists began mapping the human genome in 1911 with the study of color-blindness. Cook-Deegan, *supra* note 12, at 31. The mapping became more systematic in 1980 when an article was published in the American Journal of Human Genetics suggesting a method for identifying and organizing chromosome markers. David Botstein et al., *Construction of a Genetic Linkage Map in Man Using Restriction Fragment Length Polymorphism*, 32 Am. J. Hum. Genetics 314 (1980); see Cook-Deegan, *supra* note 12, at 29. For a short history of gene mapping, see Victor A. McKusick, *The Human Genome Project: Plans, Status, and the Application in Biology and Medicine*, in *Gene Mapping* 18, 20-26 (George J. Annas & Sherman Elias eds., 1992). For a more in-depth treatment, see generally Cook-Deegan, *supra* note 12.

22. See McKusick, *supra* note 21, at 18.

23. See *id.* at 20-26; see also William A. Haseltine, *Discovering Genes for New Medicines*, Sci. Am., Mar. 1997, at 92 (explaining how partial cDNA sequencing can yield advances against genetically related diseases).

24. Lee, *supra* note 13, at 15.

25. McKusick, *supra* note 21, at 18. The Genome Project is an international effort that began in 1990 to locate all of the human genes and make them available for further research, and to sequence all three billion DNA base pairs that make up the human genome. *Human Genome Project: Frequently Asked Questions* (visited Nov. 2, 1997) <[http://www.ornl.gov/TechResources/Human\\_Genome/faq/faq1.html](http://www.ornl.gov/TechResources/Human_Genome/faq/faq1.html)>. The Genome Project consists of the Department of Energy Human Genome Program directed by Ari Patrinos and the National Institute of Health National Human Genome Research Institute directed by Francis Collins. *Id.* For more information about the Genome Project, see *Human Genome Project Information* (visited Nov. 2, 1997) <[http://www.ornl.gov/TechResources/Human\\_Genome/home.html](http://www.ornl.gov/TechResources/Human_Genome/home.html)>. For a collection of essays about the scientific, ethical, and legal issues engendered by the Genome Project and other genetic research, see *The Code of Codes* (Daniel J. Kevles & Leroy

The proposed Human Genome Diversity Project ("Diversity Project" or "Project" or "HGDP") is a controversial spin-off of the Genome Project that intends to collect genetic samples of indigenous populations all over the globe.<sup>26</sup> Instead of mapping the entire human genome like the Genome Project, the Diversity Project plans to amass "a representative sample of human genetic variation" to be analyzed under a set of standard markers.<sup>27</sup> The resulting database would be made available to researchers.<sup>28</sup> To reach these goals, the Diversity Project plans to collect DNA from at least 500 indigenous groups throughout the world.<sup>29</sup> The Diversity Project explains its focus on indigenous people as an attempt to correct "the current bias in research in human genetics toward people of European descent."<sup>30</sup> Project participants believe that the study of genetic diversity will enhance understanding of evolution,<sup>31</sup> advance medicine,<sup>32</sup> and con-

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Hood eds., 1992), and *Genetics & Society* (Penelope Barker ed., 1995), and Alastair T. Iles, *The Human Genome Project: A Challenge to the Human Rights Framework*, 9 Harv. Hum. Rts. J. 27 (1996) (discussing the benefits and inadequacies of applying the human rights approach to the issues raised by the Genome Project). Congress has responded to the public's ethical concerns by introducing the Genetic Privacy and Nondiscrimination Act of 1997, H.R. 2198, 105th Cong. (1997), and the Genetic Confidentiality and Nondiscrimination Act of 1997, S. 422, 105th Cong. (1997).

26. The proposed project is comprised of geneticists and is run by an executive committee and regional committees for North America, China, and Europe. Henry T. Greely, *The Control of Genetic Research: Involving the "Groups Between,"* 33 Hous. L. Rev. 1397, 1415 (1997). The international geneticist Luigi Luca Cavalli-Sforza was vital in the creation of the Diversity Project and served as chair of the Executive Committee when it was formed in 1991. See Luigi Luca Cavalli-Sforza & Francesco Cavalli-Sforza, *The Great Human Diasporas: The History of Diversity and Evolution* 258-59 (Sarah Thorne trans., 1995) [hereinafter *Human Diasporas*]; Cavalli-Sforza et al., *supra* note 6. Henry T. Greely is the chair of the North American Regional Committee's ethics subcommittee. Greely, *supra*, at 1397 n.\*. An independent panel convened by the National Research Council has recently recommended that the Diversity Project receive government funding provided that it improves protection for the research subjects. See *Moratorium Sought on DNA Sampling*, Patriot Ledger, Oct. 23, 1997, available in 1997 WL 8196665 [hereinafter *Moratorium Sought on DNA Sampling*]; *Panel Endorses Global Gene Survey*, United Press Int'l, Oct. 21, 1997, available in LEXIS, News Library, Wires File. For more information about the Diversity Project, see *Human Genome Diversity Project* (visited Nov. 2, 1997) <<http://www-leland.stanford.edu/group/morrinst/HGDP.html>>.

27. Greely, *supra* note 26, at 1414-15. The organization's stated goals are to "collect, preserve, analyze, and make available genetic and ethnographic information." *Proposed Model Ethical Protocol for Collecting DNA Samples*, 33 Hous. L. Rev. 1431, 1433 (1997) [hereinafter *Model Protocol*].

28. Greely, *supra* note 26, at 1414.

29. *Id.*

30. *Model Protocol*, *supra* note 27, at 1433.

31. Greely, *supra* note 26, at 1414.

32. *Id.* at 1414-15 ("[G]reater knowledge of human genetic diversity will improve medicine, both because it will advance the study of those genetic diseases found largely in non-European populations, and because genetic variation is basic to better understanding a host of diseases found in all peoples.").

tribute to knowledge of prehistoric human migrations and expansions.<sup>33</sup>

Project representatives have stated that no sampling of indigenous people has been done in connection with the Diversity Project.<sup>34</sup> The North American Regional Committee of the proposed Diversity Project has recently published the Model Ethical Protocol for Collecting DNA Samples ("Model Protocol").<sup>35</sup> The guidelines are extensive and include discussions on mandatory informed group and individual consent,<sup>36</sup> benefits for participating communities,<sup>37</sup> privacy,<sup>38</sup> and patenting.<sup>39</sup> The Diversity Project requires that any researchers associated with the Project adhere to these research requirements.<sup>40</sup> The Diversity Project has taken a strong stand by deciding not to endorse, support, or fund researchers that violate the Model Protocol.<sup>41</sup>

Despite the Project's efforts to allay fears and rebut accusations of exploitation, many indigenous groups have spoken out strongly against it.<sup>42</sup> The Diversity Project is not, however, the only group in-

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33. *Model Protocol*, *supra* note 27, at 1433 ("The HGDP expects that its work will lead to advances in understanding the biological development and the history of our species and, ultimately, in understanding and treating many diseases with genetic components.").

34. Greely, *supra* note 26, at 1415 ("Currently, DNA collection is not yet taking place as a formal part of the HGDP."). Diversity Project chairperson, Luigi Luca Cavalli-Sforza, however, was involved in a pilot project of collecting indigenous DNA samples that began in 1984. Human Diasporas, *supra* note 26, at 256-59; *see also* L. Luca Cavalli-Sforza et al., *The History and Geography of Human Genes* (1994) (compiling and analyzing genetic data of indigenous peoples from all over the world).

35. *See Model Protocol*, *supra* note 27; *infra* Part III.B.3.

36. *Model Protocol*, *supra* note 27, at 1441-52.

37. *Id.* at 1452-56.

38. *Id.* at 1461-64.

39. *Id.* at 1466-69.

40. *Id.* at 1466-67. The Model Protocol states that the Diversity Project aims to protect the interests of the indigenous peoples by contract. *Id.* at 1468. This approach, however, does not provide adequate protection because there could be no effective enforcement against parties who obtain samples outside of a contractual relationship. *See* Greely, *supra* note 26, at 1419-20.

41. *Model Protocol*, *supra* note 27, at 1435-36. The Diversity Project has officially rejected the "bleed and run" collecting done by researchers who surface to take samples and then leave without a trace. *Id.* at 1438.

42. Indigenous peoples have objected strenuously to the Diversity Project. Several indigenous representatives have called on the international community for an end to the Diversity Project. *See Discrimination Against Indigenous Peoples: Report of the Working Group on Indigenous Populations on its Fourteenth Session*, Commission on Human Rights, Sub-Commission on Prevention of Discrimination and Protection of Minorities, 48th Sess., Agenda Item 14, at 27-28, U.N. Doc. E/CN.4/Sub.2/1996/21 (Aug. 16, 1996). The *Beijing Declaration of Indigenous Women* states: "We demand that the Human Genome Diversity Project be condemned and stopped." *Beijing Declaration of Indigenous Women*, NGO Forum, United Nations Fourth World Conference on Women, Huairou, Beijing, Peoples Republic of China, Aug. 30-Sept. 8, 1995 (visited Nov. 2, 1997) <<http://www.web.net/~csc/text/Beijing.htm>> [hereinafter *Beijing Declaration*]. A regional meeting in Malaysia of indigenous peoples produced a statement that "[t]he indigenous peoples of Asia strongly condemn the patenting and commercialization of their cell lines or body parts, as being promoted by the scientists and

terested in studying indigenous genome. While the Diversity Project is exploring how to gain access to indigenous people's genetic material by developing ethical guidelines, other researchers have already obtained samples.<sup>43</sup>

The question remains of how to enforce safeguards for indigenous peoples like those advanced in the Model Protocol.<sup>44</sup> The federal government provides indirect control of research by requiring compliance with regulations to receive federal funding.<sup>45</sup> There is also some indirect control of entities that do not receive federal funding because the Federal Drug Administration ("FDA") requires compliance with regulations and Institutional Review Board ("IRB") research approval before an application for FDA approval will be granted.<sup>46</sup> Although

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institutions behind the Human Genome Diversity Project." *Regional Meeting of Indigenous Peoples' Representatives on the Conservation and Protection of Indigenous Peoples' Knowledge Systems*, TVRC Tambunan, Sabah, Malaysia, Feb. 24-27, 1995 (visited Nov. 2, 1997) <<http://www.web.net/~csc/text/Sabah.htm>> [hereinafter *Sabah Statement*]. A group of indigenous peoples from the western hemisphere also declared that they "particularly oppose the Human Genome Diversity Project which intends to collect, and make available our genetic materials which may be used for commercial, scientific and military purposes." *Declaration of Indigenous Peoples of the Western Hemisphere Regarding the Human Genome Diversity Project*, Phoenix, Arizona, Feb. 19, 1995 (visited Nov. 2, 1997) <<http://www.indians.org/welker/genome.htm>> [hereinafter *Phoenix Declaration*]. The Canada-based World Council of Indigenous People stated that they "categorically reject and condemn the Human Genome Diversity Project." Charles J. Hanley, *Indigenous Peoples Resist Worldwide Gene Study*, L.A. Times, July 7, 1996, at A8.

Rural Advancement Foundation International ("RAFI") is an Ottawa-based international non-governmental organization "dedicated to the conservation and sustainable improvement of agricultural biodiversity, and to the socially responsible development of technologies useful to rural societies." *The Rural Advancement Foundation International* (visited Nov. 2, 1997) <<http://www.rafi.ca/>>. RAFI's Research Director, Hope Shand, has argued that "[n]o matter how well intentioned" the Diversity Project, it should not proceed until there are adequate safeguards in place. *Indigenous People and NGOs Testify Before the National Academy of Sciences Committee on the Human Genome Diversity Project* (visited Nov. 2, 1997) <<http://www.rafi.ca/pp/hgdpcomm.html>> [hereinafter *Indigenous People Testify*].

43. See *infra* Part I.D; see also Salopek, *supra* note 3 (describing genetic studies involving indigenous peoples). The President of Organizacion Nacional Indigena de Colombia ("ONIC"), Abadio G. Stocel, has spoken of "the large scale collection of indigenous peoples' blood and tissues in Colombia and how some researchers had taken advantage of the good faith of indigenous people. He explained how indigenous people were ill-informed about research being done on their cells." *Indigenous People Testify*, *supra* note 42.

44. See also National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research* (1978) (identifying guiding principles of research as the boundary between practice and research, the obligations to avoid harm and maximize benefit, and the fair distribution of benefits).

45. See, e.g., 42 U.S.C. § 3515(b) (1994) (denying federal funding to research projects that do not ensure informed consent); 45 C.F.R. § 46.109(a) (1995) (mandating Institutional Review Board ("IRB") authority to review and approve or disprove research); *id.* § 46.111 (requiring broad informed consent).

46. See 21 C.F.R. § 50.1 (1997) (stating that the regulations that follow govern FDA approval applications and investigations).

these approaches may provide some incentive for researchers to obtain the informed consent of individual subjects, these approaches are inadequate because they do not address the issue of group consent that exists when involving indigenous peoples. Also, although federal regulations provide IRBs with the authority to conduct continuing review of research policies and to observe the consent process and research, the possibility of meaningful oversight of the collection of indigenous genetic samples done in remote parts of the globe is highly questionable.<sup>47</sup> None of the current regulations can ensure the protection of indigenous peoples.

### B. Life Patents

Currently, a controversy rages over the patenting of genetic information.<sup>48</sup> The driving rationale behind the patent system is to create an incentive for creation.<sup>49</sup> Research and development in the genetics field is time-consuming, expensive, and often without any monetary payoff. The limited patent monopoly rewards the creator by building a shield against competition. If no such protections existed, some argue that research would not take place and that all research development would be kept a secret, thereby inhibiting others from building

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47. See 45 C.F.R. § 46.109(e) (1996).

48. See, e.g., Ned Hettinger, *Patenting Life: Biotechnology, Intellectual Property, and Environmental Ethics*, 22 B.C. Env't. Aff. L. Rev. 267 (1995) (questioning the appropriateness of life patents based on their costs and risks as well as a respect for life, and arguing that biopatents are not justified, but should be abolished); Kate H. Murashige, *Patent Protection for Biotechnology*, 382 PLIPat. 473 (1994) (recognizing that protection for biotechnology and sustainable development must coincide); Amy E. Carroll, Comment, *Not Always the Best Medicine: Biotechnology and the Global Impact of U.S. Patent Law*, 44 Am. U. L. Rev. 2433 (1995) (identifying a divergence of the goals of the biotechnology industry and the patent law, which may impede biotechnological progress); Barbara Looney, Note, *Should Genes Be Patented? The Gene Patenting Controversy: Legal, Ethical, and Policy Foundations of an International Agreement*, 26 Law & Pol'y Int'l Bus. 231 (1994) (recognizing both the important benefits of the patent system and the ethical issues raised by gene patents, then proposing a solution that involves the creation of an international body that would hold the human genome in trust). Moreover, controversy over patenting was one reason why James Watson left his position as director of the National Institute of Health. Cook-Deegan, *supra* note 12, at 185; Hilary Stout, *Watson Resigns as Head of U.S. Gene-Mapping Project*, Wall St. J., Apr. 13, 1992, at B9.

49. According to the U.S. Patent Act, the criteria for a patent are novelty, 35 U.S.C. § 102 (1994), nonobviousness, *id.* § 103, and utility, *id.* § 101. Once a patent is granted, the grantee has the exclusive right to make, use, or sell the invention in the United States for twenty years from the date the patent is issued. *Id.* § 154(a)(2). In exchange for the limited monopoly, the inventor must make public the advance so that others may build on it once the patent expires or through licensing. See *id.* § 112. Thus, patent law serves to reward inventiveness by protecting the commercial prospects of an industrious creator, but also encourages the advancement of technology by making the patented material available for others. See Rebecca S. Eisenberg, *Patent Rights in the Human Genome Project*, in *Gene Mapping*, *supra* note 21, at 226, 227.

on past work.<sup>50</sup> Proponents state that patenting genetic material is not unethical because “[p]atents on molecules derived from knowledge of the human genome are already in existence and they do not differ fundamentally from many other chemical patents on human health care products.”<sup>51</sup> In the midst of this debate, the United States has granted, and the Supreme Court has upheld, life patents.

The U.S. Supreme Court decided its first case about the patenting of life in *Diamond v. Chakrabarty*.<sup>52</sup> The Court held that live, human-made microorganisms were patentable subject matter.<sup>53</sup> The United States has continued to expand the definition of what is patentable based on this decision.<sup>54</sup> For example, patents are now granted for DNA sequences of proteins and predisposition to disease.<sup>55</sup> The United States has also issued patents on cell lines derived from humans.<sup>56</sup>

When asked who owned the polio vaccine, Jonas Salk responded: “[T]he people, I would say. There is no patent. Could you patent the sun?”<sup>57</sup> The famous scientist’s question implies that some things are fundamental and should not be subject to a limited patent monopoly.<sup>58</sup> Congress has proposed legislation to implement a moratorium on the patenting of genetically engineered animal life forms until a full study of the resulting ethical and moral issues could be completed.<sup>59</sup> A moratorium has never taken place, however, and life patenting con-

50. See Office of Technology Assessment, U.S. Congress, *Finding a Balance: Computer Software, Intellectual Property and the Challenge of Technological Change* 185 (1992).

51. N.H. Carey & P.E. Crawley, *Commercial Exploitation of the Human Genome: What are the Problems?*, in Ciba Foundation, *Human Genetic Information: Science, Law and Ethics* 133, 137 (1990).

52. 447 U.S. 303 (1980).

53. *Id.*

54. See Biotechnological Process Patents Act of 1995, Pub. L. No. 104-41, § 1, 109 Stat. 351, 351 (codified at 35 U.S.C. § 103(b)(3) (Supp. 1997)) (listing several biotechnological processes that may be patented). For an analysis of patent law, life patents, and the Federal Circuit, see Kenneth J. Burchfiel, *Biotechnology and the Federal Circuit* (1995).

55. See Eisenberg, *supra* note 49, at 228 n.16 (citing as examples, U.S. Patent 4,994,371 (Feb. 19, 1991) (sequence of human factor IX) and U.S. Patent 4,970,161 (Nov. 13, 1990) (incorporation of human-interferon gamma sequence)).

56. See, e.g., *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479 (Cal. 1990), *cert. denied*, 499 U.S. 936 (1991); see also Richard Gold, *Owning Our Bodies: An Examination of Property Law and Biotechnology*, 32 San Diego L. Rev. 1167, 1169 (1995) (noting that many biotechnology products are based on the human body).

57. George Johnson, *Once Again, A Man with a Mission*, N.Y. Times, Nov. 25, 1990, § 6 (Magazine), at 57, 61 (noting, however, that in fact there was nothing to patent and that National Foundation for Infantile Paralysis researchers were not entitled to receive royalties anyway).

58. Similarly, Leonor Zalabata Torres, an Arhuaco leader from the Sierra Nevada de Santa Marta, Colombia, has expressed that for her and her people: “Some things just aren’t for sale.” *Indigenous People Testify*, *supra* note 42.

59. See, e.g., Life Patenting Moratorium Act of 1993, S. 387, 103d Cong., 1st Sess. § 2(1) (1993) (suggesting a two-year moratorium on several types of life patents).

tinues in the United States to this day. In 1995, the European Parliament voted to reject a directive that would have explicitly allowed the patenting of life forms.<sup>60</sup> Although the decision did not have much of an immediate impact because patents in Europe are granted by the European Patent Office, a non-European Union body, and member nations' individual patent offices, biotechnology companies continued to lobby for passage of the directive.<sup>61</sup> Their efforts were successful when, in July 1997, the European Parliament approved an almost identical directive that must now be approved by both the European Union executive office and member states' governments.<sup>62</sup> As discussed in the next section, these patents have engendered a controversy in the context of the genetic research of indigenous peoples.

### C. Scope of the Problem

Many indigenous groups do not believe that outsiders should take samples and conduct research on their genetic material.<sup>63</sup> They feel that it is molecular colonialism and fear that indigenous peoples will be harvested for genetic samples with no compensation.<sup>64</sup> Some raise concerns about whether indigenous peoples are capable of giving their informed consent because they lack the sophistication to understand genetic research.<sup>65</sup> Genetic patenting is antithetical to some indige-

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60. Nigel Hawkes, *Euro MPs Turn Down Life-Forms Patent Law*, Times (London), Mar. 2, 1995, available in 1995 WL 7652787; see also Ethics and Human Genetics, Proceedings 2nd Symposium of the Council of Europe on Bioethics, Strasbourg, Nov. 30-Dec. 2, 1993, at 95-114 (discussing the proposed directive and whether the human genome should be patentable).

61. *Id.*; Alan Simpson, *The Theft of Our Souls*, Guardian, July 11, 1997, at 19.

62. *Europe Gives Green Light to Gene Law*, Independent, July 17, 1997, at 2; see Simpson, *supra* note 61, at 19.

63. See, e.g., *Phoenix Declaration*, *supra* note 42 ("We demand an immediate moratorium on collections and/or patenting of genetic materials from indigenous persons and communities by any scientific project, health organization[,] governments, [i]ndependent agencies, or individual researchers.").

64. See, e.g., *Sabah Statement*, *supra* note 42 (stating that patenting indigenous genetic material "is akin to robbing indigenous peoples of their resources and knowledge through monopoly rights"); *Beijing Declaration*, *supra* note 42 ("Bioprospecting, which is nothing but the alienation of our invaluable intellectual and cultural heritage through scientific collection missions and ethnobotanical research, is another feature of recolonization.").

65. See, e.g., *Sabah Statement*, *supra* note 42 ("The technological method of piracy is too sophisticated for indigenous peoples to understand, especially when indigenous communities are unaware of how the system operates and who are behind it."). Debra Harry, a Pauite Indian, thinks it is "impossible for scientists to give indigenous populations informed information, to explain what they are doing with this DNA." Leslie Alan Horvitz, *'Vampire Project' Raises Issue of Patents for Human Genes*, Insight Mag., July 22, 1996, available in 1996 WL 11224474. This opinion may underestimate human capabilities. First world nations have been taking advantage of indigenous peoples for centuries, but categorical denial of their capacity may unjustly limit them. The process by which to achieve informed consent, however, is much more involved than with members of an industrial state. One major hurdle is language, and another is lack of exposure to scientific ideas. Many indigenous groups

nous belief systems.<sup>66</sup> Although diagnostic tools or cures may be discovered, many indigenous populations may never benefit because they live so far away from medical centers.<sup>67</sup> Others opposed to this research express concern about the purpose of the genetic databases and fear that the information could be used to harm indigenous peoples.<sup>68</sup> Some believe that the millions of dollars spent to do the re-

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simply will not have the language of genetics or western science. This obstacle, however, is not insurmountable.

For discussions about informed consent, human rights, and regulating human experimentation, see Jesse A. Goldner, *An Overview of Legal Controls on Human Experimentation and the Regulatory Implications of Taking Professor Katz Seriously*, 38 St. Louis U. L.J. 63 (1993), and Jay Katz, *Human Experimentation and Human Rights*, 38 St. Louis U. L.J. 7 (1993).

66. As illustrated by the Guaymi example, *infra* notes 75-83 and accompanying text, some indigenous groups believe that it is against nature to patent human genetic information, and some think it is wrong to patent any life genetic information. See, e.g., *Beijing Statement*, *supra* note 42 ("We call for a stop to the patenting of all life forms. This to us, is the ultimate commodification of life which we hold sacred."); *Sabah Statement*, *supra* note 42 ("For indigenous peoples, life is a common property which cannot be owned, commercialized and monopolized by individuals."). Group Two in the hypothetical is also concerned with this issue.

Indigenous groups have a wide variety of religious or spiritual beliefs. As with many aspects of indigenous culture, the range is so vast as to defy sweeping generalizations. There are, however, some discernible trends that center around respect for nature, land, and life. Indigenous life has been reliant on and sustained by nature in a direct way, such that native groups tend to view nature and the naturally occurring world as sacred. For example, the *1995 Summary of the Issues Affecting Indigenous Women: Fourth World Conference on Women* stated:

To Indigenous Peoples, our spiritual ties to Mother Earth and respect for all living creatures are . . . a way of life. Our survival is dependent upon our inherent right to practice our traditional ways and teachings which have been given to us by the Creator. . . . To us, the Earth and everything upon it is sacred.

*Summary of the Issues Affecting Indigenous Women: Fourth World Conference on Women*, Beijing, China (Sept. 4-15, 1995) [hereinafter *Fourth World Conference*]. The *Phoenix Declaration* provides another example:

Our principles are based upon our profound belief in the sacredness of all Creation, both animate and inanimate. We live in a reciprocal relationship with all life in this divine and natural order.

. . . .

We hold precious all life in its natural form. The harmonious progress of the natural order in the environment shapes and defines healthy genetic diversity.

The principle of harmony requires that we do not violate the principles of Creation by manipulating and changing the natural order.

*Phoenix Declaration*, *supra* note 42.

67. Anthropologist Jonathan Friedlaender, of Temple University, recognizes that tribes "aren't going to benefit from any new drugs out of this stuff because the medical care system there is primitive." Teresa Riordan, *A Recent Patent on a Papua New Guinea Tribe's Cell Line Prompts Outrage and Charges of Biopiracy*, N.Y. Times, Nov. 27, 1995, at D2.

68. See Kathy Holliman, *Gene Research Probes Indian Alcoholism*, Bangor Daily News, June 22, 1996, available in 1996 WL 10701920.

search should go to help save indigenous people from more immediate threats such as malaria and starvation.<sup>69</sup>

Genetic researchers believe that much of the criticism aimed at them is because their work is "easily misunderstood and demagogued."<sup>70</sup> In fact, not all indigenous people are against genetic research and patenting. Some indigenous people are interested in learning more about their migratory history.<sup>71</sup> Other indigenous groups suffer from diseases and want to participate in this research, hoping to facilitate the development of a cure that will benefit them.<sup>72</sup>

As discussed above, the ethical guidelines created by the Diversity Project require that researchers obtain the informed consent of indigenous people before collecting samples.<sup>73</sup> The guidelines also discuss the difficult questions relating to adequate compensation for indigenous groups for their participation.<sup>74</sup> Problems arise when, as in the introductory hypothetical, people are not fully informed or are not adequately compensated. As discussed below, there are no laws that explicitly address the hypothetical cases. Human rights principles, however, should provide redress for indigenous peoples confronted with this situation.

#### D. *Recent Incidents with Indigenous Groups*

An increasing number of incidents involving indigenous sampling and patenting exemplify the issues that arise at the nexus of indige-

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69. See Horvitz, *supra* note 65; see also *Phoenix Declaration*, *supra* note 42 ("We demand that scientific endeavors and resources be prioritized to support and improve social, economic and environmental conditions of indigenous peoples in their environments, thereby improving health conditions and raising the overall quality of life."); *Indigenous People Testify*, *supra* note 42 (quoting Ruth Liloqula, Director of the Agricultural Research of the Government of the Solomon Islands, who testified in personal capacity, that the Diversity Project's research agenda was not in line with her country's priorities and that they were more concerned with diseases like malaria, not on historical migrations, and stated: "We know who we are.").

70. Sally Lehrman, *NIH Forfeits Rights to Patent on Papua New Guinea Cell Line*, *Biotechnology Newswatch*, Jan. 6, 1997, available in 1997 WL 8790236 (quoting Hank Greely, chair of the Diversity Project's ethics subcommittee and Stanford University professor of law).

71. Doug George from the Iroquois Confederacy in Central New York noted that the genetic information may help tribes interested in their migratory history by confirming ancient stories. Holliman, *supra* note 68.

72. One example of an indigenous group that is pleased with their involvement in genetic research is the Sandy Lake Band from Northern Ontario who have an agreement with the Samuel Lunenfeld Research Institute at Toronto's Mount Sinai Hospital. *Band Reaches Deal in Diabetes Study*, *Vancouver Sun*, Mar. 30, 1996, at A4. Researchers hope that, with the help of the groups' blood, they may be able to develop a cure for diabetes. *Id.* Data becomes the property of the band and the band gets veto power as to what happens to their genetic material and 20% of any profits. *Id.* The band's Chief Eli Sawanas is quoted as saying, "We knew what we wanted from the research . . . We've been involved from the beginning. There hasn't been any part of the research we haven't been aware of." *Id.*

73. See *supra* notes 36-40 and accompanying text.

74. *Model Protocol*, *supra* note 27, at 1452-56, 1466-68.

nous peoples and genetic research. Some scientists and patenting nations have ignored the possibility that indigenous peoples' belief systems may be incompatible with industrialized intellectual property systems.<sup>75</sup> One situation involved the Guaymi, an indigenous group inhabiting Panama. In the early 1990s, the U.S. Department of Commerce submitted a patent application on the cell line of a Guaymi woman.<sup>76</sup> The cell line was believed to have anti-viral qualities.<sup>77</sup> Rural Advancement Foundation International ("RAFI")<sup>78</sup> found the application while going through a database of patent applications and contacted the Guaymi people.<sup>79</sup> Neither the tribe nor the woman knew anything about the development of the cell line or the patent application.<sup>80</sup> Rural Advancement and other groups supported the Guaymi in their demand for withdrawal of the patent application.<sup>81</sup> The Guaymi tribal president explained, "[i]t's fundamentally immoral, contrary to the Guaymi view of nature, and our place in it. To patent human material . . . to take human DNA and patent its products . . . violates the integrity of life itself, and our deepest sense of morality."<sup>82</sup> Later that year, due to international pressure, the Center for Disease Control withdrew the patent application.<sup>83</sup>

Another concern is that emerging policy is currently defined by government departments and agencies, as was evidenced by the response of the U.S. Department of Commerce when the people of the Solomon Islands were the subject of a cell line patent application.<sup>84</sup> When their government became aware of the application, its United Nations ambassador wrote a letter of protest to the U.S. Department of Commerce.<sup>85</sup> Former Department Secretary Ron Brown stated in response: "Under our laws, as well as those of many other countries, subject matter relating to human cells is patentable and there is no

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75. See, e.g., *Sabah Statement*, *supra* note 42 ("Based on this worldview, indigenous peoples find it difficult to relate intellectual property rights issues to their daily lives. Accordingly, the patenting of any life forms and processes is unacceptable to indigenous peoples.").

76. Philip L. Bereano, *Patent Pending: The Race to Own DNA*, *Seattle Times*, Aug. 27, 1995, at B5.

77. *Id.*

78. For a description of the organization, see *supra* note 42.

79. Bereano, *supra* note 76, at B5.

80. *Id.*

81. *Id.*

82. *Id.*

83. *Id.*

84. *Id.*

85. Letter from Ambassador Rex Horoi to the U.S. Department of Commerce (Feb. 1, 1994) (visited Nov. 2, 1997) <<http://www.rafi.ca/pp/hotobr.html>>; see Bereano, *supra* note 76, at B5.

provision for considerations relating to the source of the cells that may be the subject of a patent application."<sup>86</sup>

Furthermore, in the absence of stringent international guidelines governing genetic research, it is often unclear whether indigenous cooperation is really exploitive. One example involved the Hagahai, a tribe from the Madang Province of Papua New Guinea. The tribe, described as a 260-member group of hunter-horticulturists, did not have any contact with outsiders until 1984 when some tribe members sought outside help for illness that plagued the group.<sup>87</sup> During the course of attempting to discover how to help the Hagahai people, researchers discovered that several members of the tribe were infected with the human T-cell leukemia virus ("HTLV-I") that usually produces severe leukemia, but is benign in the Hagahai.<sup>88</sup> Scientists created an HTLV-infected cell line of Hagahai DNA that was thought may be valuable in developing a diagnostic tool or vaccine.<sup>89</sup> The cell line was patented and researchers were listed as the "inventors."<sup>90</sup>

The patent quickly became the focus of international attention.<sup>91</sup> The Papua New Guinea government questioned whether the patent claim violated that nation's sovereignty.<sup>92</sup> Non-governmental organizations claimed that the incident was another example of biodiversity prospecting—or "biopiracy."<sup>93</sup> Researchers claimed to have discussed the idea of the patent with the tribe and asserted that the tribe had a clear understanding of the concept of ownership,<sup>94</sup> and that the re-

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86. Letter from former Department of Commerce Secretary Ron Brown to Solomon Islands United Nations Ambassador Rex Horoi (Mar. 3, 1994) (visited Nov. 2, 1997) <<http://www.rafi.ca/pp/btrtoho.html>>; see Bereano, *supra* note 76, at B5.

87. See Gary Taubes, *Scientists Attacked for 'Patenting' Pacific Tribe*, *Science*, Nov. 17, 1995, at 1112.

88. Riordan, *supra* note 67. With the New Guinea Institute of Medical Research ("IMR"), health workers collected blood samples from the tribe and sent them to the gene bank at the U.S. National Institute of Health ("NIH"). See Taubes, *supra* note 87.

89. Nigel Hawkes, *Tribal Treasure*, *Times* (London), Mar. 4, 1996, available in LEXIS, Nexis Library, Majpap File; Taubes, *supra* note 87.

90. On February 13, 1996, Patent No. 5,397,696 for a "Papua New Guinea human T-lymphotropic virus" was assigned to the U.S. Department of Health and Human Services. Riordan, *supra* note 67. NIH claimed to have patented the cell line to clarify the rights for private companies who might want to use the cell line to develop diagnostic tests for HTLV-I. Taubes, *supra* note 87.

91. See Lehrman, *supra* note 70.

92. *Tempest Ending for 'Cell Line:' U.S. Stepping Back from Genetic Patent*, *Arizona Republic*, Sept. 22, 1996, at A18 [hereinafter *Tempest*].

93. David Robie, *Biotechnology-South Pacific: Tribe Caught in Blood Tug-of-War*, *Inter Press Service*, Oct. 25, 1995, available in 1995 WL 10135200.

94. There was apparently an agreement, the details of which are unclear, that the people were to receive royalties that came from any commercial viability. Taubes, *supra* note 87; see also Lehrman, *supra* note 70 ("[S]cientists involved with the HTLV-1 application said they felt compelled to establish some precedent to protect the Hagahai interest in their own tissue, since Papua New Guinea has no patent laws or other regulations governing the usage of biological materials or intellectual property rights.").

searchers only proceeded after securing their approval.<sup>95</sup> The patent proved not to have any commercial value.<sup>96</sup> NIH offered to transfer the patent rights to a trust benefiting the remote tribe, but biotech companies showed no interest in buying it.<sup>97</sup> The researchers opposed a patent transfer to the tribe claiming that it was too expensive and, instead, decided to abandon the patent.<sup>98</sup> On October 24, 1996, NIH forfeited its rights to the patent at the U.S. Patent and Trademark Office ("PTO").<sup>99</sup>

These examples show the problems that result from indigenous genetic research. Researchers and nations that grant patents may disregard indigenous beliefs fundamentally incompatible with such grants. Government agencies and departments can easily dismiss indigenous complaints. With no clear guidelines firmly in place, it is difficult to determine whether indigenous people were taken advantage of or whether they participated in research after giving fully informed consent.

## PART II. THE CURRENT STATE OF THE LAW

Neither domestic nor international law explicitly provide a remedy for indigenous peoples whose genetic material has been collected or used against their wishes. This part outlines the present inadequacies of domestic and international law.

### A. *Domestic Common Law is Currently Inadequate*

Neither Congress nor U.S. courts have directly addressed the rights of indigenous people in connection with genetic sampling and patenting. One case, however, looms large in the area of genetic research, and has spawned much debate about body part ownership.<sup>100</sup> In

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95. Taubes, *supra* note 87. The Papua New Guinea government almost deported one researcher involved, but subsequently exonerated her from wrongdoing, determining that she had obtained the full consent of the tribe. Lehrman, *supra* note 70.

96. Riordan, *supra* note 67 (citing Greely).

97. *Tempest*, *supra* note 92, at A18.

98. *Id.*; Lehrman, *supra* note 70.

99. Lehrman, *supra* note 70 (citing to the notice of the patent disclaimer that was published December 10, 1996 in the PTO's Official Gazette).

100. See, e.g., Joseph M. Healey, Jr. & Kara L. Dowling, *Controlling Conflicts of Interest in the Doctor-Patient Relationship: Lessons from Moore v. Regents of the University of California*, 42 Mercer L. Rev. 989 (1991) (examining *Moore*, the doctor-patient relationship as a fiduciary duty, and conflicts of interest); Catherine Caturano Horan, Note, *Your Spleen is Not Worth What It Used to Be: Moore v. Regents of UCLA*, 24 Creighton L. Rev. 1423 (1991) (arguing that the informed consent requirement raises the possibility that a patient's decision-making will be confused, and that the court's decision to deny Moore recognition of property rights creates inequities in research); Stephen Ashley Mortinger, Comment, *Spleen for Sale: Moore v. Regents of the University of California and the Right to Sell Parts of Your Body*, 51 Ohio St. L.J. 499 (1990) (arguing that the California Court of Appeals, which was later reversed by the California Supreme Court, correctly held that Moore had a protectable property interest in his excised cells).

*Moore v. Regents of the University of California*,<sup>101</sup> the California Supreme Court addressed the protocol and rights surrounding genetic sampling, research, and patenting of a cell line derived from a U.S. citizen's cells. The court was faced with the decision of whether to recognize a cause of action for the unauthorized use of a patient's cells for commercial gain.<sup>102</sup>

John Moore was diagnosed with hairy-cell leukemia, a rare form of cancer.<sup>103</sup> During treatment, his physician withdrew excess samples of blood and performed a splenectomy without informing Moore that his spleen and blood samples were going to be used in research.<sup>104</sup> The physician and researchers developed a cell line from those samples.<sup>105</sup> The cell line proved lucrative, and Moore sued the physician and researchers on several grounds, including breach of fiduciary duty and conversion. He argued that his physician and the researchers breached their fiduciary duty by failing to inform him that they were taking excess samples and of their economic interest in the research.<sup>106</sup> Moore also argued that he had a property interest in his excised cells and, thus, that the defendants' unauthorized actions constituted a conversion.<sup>107</sup>

The court ruled that Moore had a right to be fully informed by his physician—that Moore could maintain a cause of action alleging that the doctor breached his fiduciary duty to inform Moore of the research.<sup>108</sup> Moore could not, however, maintain a cause of action against the researchers because the court held that the researchers owed no fiduciary duty to Moore.<sup>109</sup> Moreover, the court decided that Moore was not entitled to property rights in his excised cells.<sup>110</sup> This

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101. 793 P.2d 479 (Cal. 1990).

102. *Id.* at 480.

103. *Id.* at 480-81.

104. *Id.* at 481 (including in the list of excess biological material obtained by the doctor: blood serum, skin, bone marrow aspirate, and sperm).

105. *Id.*

106. *Id.* at 483, 486; see *infra* Part II.A.1.

107. *Moore*, 793 P.2d at 487; see *infra* Part II.A.2.

108. *Moore*, 793 P.2d at 486. For a discussion of fiduciary duty, see *infra* Part II.A.1.

109. *Moore*, 793 P.2d at 486.

110. *Id.* at 497. There are many ethical issues involved in the treatment of genetic material as property. See Richard Gold, *Owning Our Bodies: An Examination of Property Law and Biotechnology*, 32 San Diego L. Rev. 1167 (1995) (suggesting that recognizing property rights in genetic material would inappropriately focus on the market aspects of the body and health); Peter Halewood, *Law's Bodies: Disembodiment and the Structure of Liberal Property Rights*, 81 Iowa L. Rev. 1331 (1996) (arguing that a relational property theory—in which the context and appropriate interests drive the decision in disputes where biotechnology commodifies the body—should replace conventional liberal and market-inalienability property theories); Judith B. Prowda, *Moore v. The Regents of the University of California: An Ethical Debate on Informed Consent and Property Rights in a Patient's Cells*, 77 J. Pat. & Trademark Off. Soc'y 611, 629-32 (1995) (questioning the validity of the *Moore* court's reasoning and conversion holding); Sharon N. Perley, Note, *From Control Over One's Body to Con-*

part examines why the *Moore* decision falls short of adequately protecting indigenous peoples, but concludes that the decision does not preclude enhanced protection for indigenous peoples.

### 1. Fiduciary Duty and Informed Consent

The *Moore* court ruled that Moore's doctor owed him a fiduciary duty. A fiduciary duty is a duty to act in another's interest at the expense of one's personal interest.<sup>111</sup> A fiduciary relationship arises between parties when one side must rely on and trust the other, who is in a position of power or domination.<sup>112</sup> If a court decides that a fiduciary relationship is so important as to create a fiduciary duty, a breach of that duty gives rise to a tort.<sup>113</sup>

The doctrine of informed consent stems from a doctor's duty to a patient and recognizes the patient's right to self-determination and autonomy.<sup>114</sup> It encompasses the general principle that, for a patient to

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*trol Over One's Body Parts: Extending the Doctrine of Informed Consent*, 67 N.Y.U. L. Rev. 335 (1992) (arguing that the informed consent doctrine should be expanded to protect a patient's dignitary interest in excised cells); Catherine M. Valerio Barrad, Comment, *Genetic Information and Property Theory*, 87 Nw. U. L. Rev. 1037, 1085-86 (1993) (stating that when evaluating the unmeasurable competing interests of a person whose genetic material has been used by a researcher, a court should resist the temptation to be swayed by the inevitable bias to decide based on a utilitarian influence to benefit the larger group of people and societal interests).

111. Black's Law Dictionary 625 (6th ed. 1990). The *Moore* court recognized that a fiduciary duty could be viewed as a broad concept. Indeed, the court indicated that the term "fiduciary" was, in some ways, too broad because the doctor was not responsible to protect the patient's financial interests as the term implied. Rather, the court ruled that there was a duty "because certain personal interests may affect professional judgment." *Moore*, 793 P.2d at 485 n.10.

112. Black's Law Dictionary 626 (6th ed. 1990). Some common examples of this relationship that give rise to a legal duty are between attorney and client, see Restatement (Third) of the Law Governing Lawyers § 28 (Proposed Final Draft No. 1, Mar. 29, 1996), and principal and agent, see Restatement (Second) of Agency § 13, cmt. a (1958).

113. See Restatement (Second) of Torts § 874 reporters' note (1982); W. Page Keeton et al., Prosser and Keeton on Torts, § 53, at 356-59 (5th ed. 1984).

114. The Supreme Court in *Cruzan v. Director, Missouri Department of Health* acknowledged that the doctrine of informed consent had become firmly entrenched in American tort law. 497 U.S. 261, 269 (1990). The Court referred to one of its prior decisions which "observed that '[n]o right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.'" *Id.* (quoting *Union Pac. R.R. Co. v. Botsford*, 141 U.S. 250, 251 (1891)); see *Schloendorff v. Society of the N.Y. Hosp.*, 211 N.Y. 125, 129-30 (1914) (Cardozo, J.) ("Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent, commits an assault, for which he is liable in damages."); Katz, *supra* note 65, at 9 ("The requirements of consent and informed consent, based on principles of autonomy and self-determination, became central prescriptions for the protection of subjects of research." (citations omitted)); see also Keeton, *supra* note 113, § 32, at 190 ("The informed consent doctrine is based on principles of individual autonomy, and specifically on the premise that every person has the right to determine what shall be done to his own body.").

make an educated decision about whether to agree to treatment, the doctor must explain information that would be material to the decision.<sup>115</sup> A patient claiming that a doctor failed to obtain informed consent must prove that the undisclosed information was material and that there was a causal link between the nondisclosure and the harm.<sup>116</sup>

The *Moore* court ruled that a physician could breach a fiduciary duty to a patient by failing to obtain the patient's informed consent prior to performing a medical procedure and, subsequently, using the patient's biological material for research.<sup>117</sup> The court acknowledged "three well-established principles:" First, that adults have a right to exercise control over their bodies and decide whether to submit to medical treatment; second, that effective patient consent must be informed; and third, that physicians are under a fiduciary duty to disclose material information.<sup>118</sup> The court concluded that the required disclosure included any interest that might affect the physician's judgment, even if that interest was unrelated to the patient's health.<sup>119</sup>

Accordingly, the court held that Moore had a cause of action against his treating physician for breach of fiduciary duty because the physician failed to obtain his informed consent by neglecting to disclose his research and economic interests in Moore's cells.<sup>120</sup> Specifically, the physician neglected to inform Moore of his "prior formed intent" to access Moore's rare biological material for research and commercial purposes.<sup>121</sup> According to the *Moore* court, however, no recovery was available against the researchers because there was no contact between the researcher defendants and Moore.<sup>122</sup>

*Moore* is of limited assistance to the indigenous people of the hypothetical groups from the introduction. Under the above analysis, plaintiffs from hypothetical Group One should be able to recover damages from the physician because, like Moore's, their samples were obtained in the course of medical treatment without disclosure of the physician's research and commercial incentives. Groups Two and

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115. Keeton, *supra* note 113, § 32, at 190-92. In the context of epidemiological studies, a person gives informed consent if she understands the study's purpose, nature, requirements, risks, and benefits. See Council for International Organizations of Medical Science, International Guidelines for Ethical Review of Epidemiological Studies (1991).

116. Keeton, *supra* note 113, at 190-92.

117. *Moore*, 793 P.2d at 483.

118. *Id.*

119. *Id.*

120. *Id.* at 485, 497.

121. *Id.* at 485.

122. *Id.* at 486. The court left undecided, however, whether the researchers could be held secondarily liable based on the doctor's non-disclosure. *Id.* at 486-87. The court had disdain for Moore's "generic boilerplate" secondary-liability allegations and noted that Moore had not alleged in his complaint that any of the researchers knew that he had not been fully informed. *Id.* at 486 n.12.

Three had direct contact with the Researchers who solicited their genetic samples. These groups could attempt to convince a court that Researchers should be held to a duty to fully inform potential subjects with whom they have direct contact. *Moore* offers no direct protection to Groups Two and Three, however, because the holding was limited to physicians.

The informed consent route to liability is severely limited as to Group One researchers because Group One did not have direct contact with the Researchers who obtained the genetic samples through the physician at the health clinic. The Researchers of Group One would not be liable under *Moore* because they did not have the kind of direct contact with the group that might give rise to a duty to inform.<sup>123</sup>

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123. Despite the *Moore* court's treatment of the researchers, a court could recognize that researchers who did not have direct contact with an indigenous people nonetheless have a duty to ensure that they are informed about the research. A court is free to recognize a new duty where it decides the plaintiff ought to be protected. See Keeton, *supra* note 113, § 53, at 359; see also *Tarasoff v. Regents of the Univ. of Cal.*, 551 P.2d 334, 342 (Cal. 1976) (“[L]egal duties are not discoverable facts of nature, but merely conclusory expressions that, in cases of a particular type, liability should be imposed for damage done.”). The conception of legal duties change along with the court's view of human relations and social conditions. *Id.* (“Changing social conditions lead constantly to the recognition of new duties.”); Joseph W. Glannon, *The Law of Torts* 174 (1995) (“[D]uties . . . are not immutable truths; they are pragmatic policy judgments that may be reconsidered by future judges as society and public attitudes evolve.”). Courts have recognized torts based on a breach of a fiduciary relationship in situations where the relationship is less direct than that between a doctor and patient. See, e.g., *Zimpel v. Trawick*, 679 F. Supp. 1502, 1511 (W.D. Ark. 1988) (holding that defendants had a duty to disclose information to an unsophisticated, seriously ill vendor where defendants had knowledge superior to that of the vendor); *Winkler v. Rocky Mountain Conference of the United Methodist Church*, 923 P.2d 152, 157-58 (Colo. Ct. App. 1995) (ruling that the pastor and church had entered into a fiduciary relationship with a parishioner who sued for breach of that duty when the pastor allegedly touched her in an inappropriate manner), *cert. denied*, 117 S. Ct. 771 (1997). Courts consider several factors when deciding whether to recognize a duty, including convenience of administration, foreseeability of the harm, burden on the defendant to avert future harm, the sophistication of the parties, and moral blame. See Keeton, *supra* note 113, § 54, at 359; Glannon, *supra*, at 173-74.

All of the factors that courts consider in deciding whether to recognize a duty support the conclusion that even researchers who do not have direct contact with an indigenous people should be held to owe a legal duty to fully inform them about genetic research and patenting. For one, it would not be excessively difficult to administer claims of indigenous people alleging that researchers breached a duty to fully inform. Although something as simple as a signed consent form would not suffice to prove full disclosure and the consent of an indigenous people as a group, a court could determine whether the researcher's actions fulfilled the duty in a particular case. A second factor that supports the recognition of a duty is the foreseeability of the harm. The *Moore* court protected the researchers by characterizing them as having “no reason to believe that their use of a particular cell sample is, or may be, against a donor's wishes.” *Moore*, 793 P.2d at 493. Researchers interested in studying the genetic makeup of indigenous people should be aware that this type of research may be against the wishes of the people because of the recent incidents of indigenous people protesting the use of their genetic material. Third, recognizing a duty of researchers to obtain the informed consent of indigenous peoples before including them

## 2. Property Rights

In its attempt to protect researchers and the biotechnology industry, the *Moore* court decided that recognition of a property right for Moore's excised cells was inappropriate and denied Moore's tort claim of conversion.<sup>124</sup> Conversion is the unauthorized exercise of control over goods belonging to another.<sup>125</sup> Such control must alter the condition of the goods, or exclude the owner from enjoying property rights.<sup>126</sup> Again, the court declined to recognize a legal duty "to investigate the consensual pedigree of each human cell sample used in research" on the biotechnology industry.<sup>127</sup>

The court concluded that existing property law did not support a recognition of property rights in Moore's cells, and went on to decide that conversion liability should not be extended.<sup>128</sup> First, it concluded that the policy considerations involved in protecting a patient's right to make a competent medical decision and protecting parties engaged in "socially useful" activities weighed in favor of avoiding any chilling effect liability might have on the biotechnology industry.<sup>129</sup> Second, the court believed that the legislature should determine whether to impose liability for the scientific use of human cells because the legislature was better suited to consider the complex policy issues involved.<sup>130</sup> Third, the court felt no pressing need to impose the strict liability tort of conversion where the plaintiff could recover on another theory, as the court had recognized the physician's duty to inform.<sup>131</sup>

The driving force behind the court's decision was a desire to avoid a chilling effect on the industry that would stunt the free flow of infor-

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in genetic studies would not create too heavy of a burden on the researchers. Researchers could adhere to informed consent procedures designed to protect indigenous peoples and ensure full disclosure. Genetic studies of indigenous peoples would be on a smaller scale and easier to keep track of than a large number of samples gathered from all over the country. Although the effort required from researchers is not negligible, recognition of the duty would not impose an undue burden when balanced against the gravity of the potential harm. The *Moore* court was largely concerned with protecting researchers who, in the court's opinion, were "engaged in socially useful activities." *Id.* A study that may be considered "socially useful" in the United States, however, may not be considered "socially useful" to an indigenous people. Indigenous peoples may consider such research to be socially harmful, against nature and morality.

124. *Moore*, 793 P.2d at 495 (comparing its decision to not expand tort liability in this case with a previous decision to avoid frustrating the pharmaceutical industry by imposing strict liability (citing *Brown v. Superior Court*, 751 P.2d 470 (Cal. 1988))).

125. Black's Law Dictionary 332 (6th ed. 1990).

126. *Id.*

127. *Moore*, 793 P.2d at 487.

128. *Id.* at 488-89, 493.

129. *Id.* at 493-94.

130. *Id.* at 493, 496.

131. *Id.* at 493, 496-97.

mation due to the ubiquitous specter of litigation.<sup>132</sup> The *Moore* court reasoned that if researchers and pharmaceutical companies, acting in good faith, are not assured of their property right in genetically derived products, the economic incentive to participate in research and development would be destroyed.<sup>133</sup> The court did not want to inhibit access to the “[t]housands of human cell lines” that were already in tissue repositories.<sup>134</sup> Thus, the *Moore* conversion holding offers no protection for the three hypothetical groups.<sup>135</sup> *Moore* fails to provide

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132. *Id.* at 494. *But see* Laura M. Ivey, Comment, *Moore v. Regents of the University of California: Insufficient Protection of Patients' Rights in the Biotechnological Market*, 25 Ga. L. Rev. 489 (1991) (arguing that the court wrongly decided the conversion issue, in part because it over-emphasized research protection at the expense of patient rights).

133. *Moore*, 793 P.2d at 495.

134. *Id.* at 494.

135. The *Moore* court conceded, however, that it could not rule that there were no circumstances under which excised cells could be recognized under a property theory. *Id.* at 493. Even if the *Moore* court's premise—that the biotechnology industry would be stunted if a property right in genetic material was recognized—is correct in cases like *Moore's*, it is not a sufficient justification to tip the scales when balanced against the unique concerns of indigenous peoples. The burden on researchers that would be created by recognizing a property interest in indigenous peoples' excised cells and any marketable derivative would not have the crippling effect feared by the *Moore* court. The *Moore* court characterized the uncertainty of title as a “ticket in a litigation lottery” for those researchers who did not have any control over the collection of samples, but who later obtain and use the samples in research. *Id.* at 495-96. Instead of deciding not to participate in research with an indigenous people, however, researchers could simply require proof of the indigenous people's fully informed consent and an agreement as to property interests to shield themselves from the liability that would result from working with an illegally-obtained sample. These researchers are not unable to protect themselves. Rather, they could negotiate an express warranty that the genetic sample was free from defects, thus providing themselves with recourse against the seller. *See* U.C.C. § 2-313(1)(a) (1996) (stating that express warranties by the seller are created by “[a]ny affirmation of fact or promise made by the seller to the buyer which relates to the goods and becomes part of the basis of the bargain”).

Another compelling reason to recognize indigenous peoples' property right to their genetic material is to avoid enforcing Western property norms to the detriment of indigenous peoples. The Western property model is inconsistent with many indigenous conceptions of property because it fails to acknowledge ideas of group ownership and collective symbolism. *See* Theresa Simpson, Note, *Claims of Indigenous Peoples to Cultural Property in Canada, Australia, and New Zealand*, 18 Hastings Int'l & Comp. L. Rev. 195, 196 (1994); *see also* Craig D. Jacoby & Charles Weiss, *Recognizing Property Rights in Traditional Biocultural Contribution*, 16 Stan. Envtl. L.J. 74 (1997) (proposing a new property rights theory that would protect the biocultural contributions of indigenous peoples). Indigenous people more often hold property in common and, in some cases, cannot alienate something that holds meaning for the group without collective assent. *See*, for example, a statement issued by the Coordinating Body of Indigenous Organisations of the Amazon Basin (“COICA”):

For members of indigenous peoples, knowledge and determination of the use of resources are collective and intergenerational. No indigenous population, whether of individuals or communities, nor the government can sell or transfer ownership of resources which are the property of the people and which each generation has an obligation to safeguard for the next.

full protection for indigenous peoples. The next section examines international law in search of protection for indigenous peoples.

### B. *International Human Rights Law is Currently Inadequate*

International human rights law is not static, but has an ever-changing and often-confusing landscape. Both positive law instruments, such as treaties, and customary international law, are binding on nations. Unfortunately, neither directly addresses indigenous peoples' concerns about their genetic material.

Positive international law includes treaties, or other international agreements, by which states have explicitly pledged to abide.<sup>136</sup> There is no international instrument directly addressing the sampling and patenting of indigenous peoples' genetic material that is binding on the United States.<sup>137</sup> The United States has signed onto international documents, however, that recognize rights relevant to indigenous peoples' control over their genetic material and which may help provide

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*COICA Statement*, Santa Cruz de la Sierra, Bolivia, Sept. 28-30, 1994, art. I, § 7 (visited Nov. 2, 1997) <<http://users.ox.ac.uk/~wgtrr/coica.htm>> [hereinafter *COICA Statement*]; cf. John Moustakas, Note, *Group Rights in Cultural Property: Justifying Strict Inalienability*, 74 Cornell L. Rev. 1179, 1184-85 (1989) (arguing for the strict inalienability of property that is strongly related to a group's identity, the retention of which would not create bad object relations). To impose liability for only the breach of a duty to fully inform would limit an indigenous peoples' recovery to damages for the harm caused by the breach of that duty. A denial of property rights would preclude indigenous peoples from enjoying the benefits that accompany such rights, including the ability to enjoin use of their genetic material, or to share in the profit should a lucrative product be developed from their genetic material.

136. Restatement (Third) of the Foreign Relations Law of the United States §§ 102(1)(b), 102(3), 111(1) (1987) [hereinafter Restatement (Third)]. A treaty between nations is like a contract between private parties and generally creates binding obligations only for the parties that agree to be bound. *See id.* §§ 321, 102 cmt. f.

137. Although Article 15(1) of the United Nations Conference on Environment and Development: Convention on Biological Diversity, 31 I.L.M. 818 (1992) (opened for signature June 5, 1992, entered into force Dec. 29, 1993), vests control of access to genetic resources with the national governments of the state parties to the treaty, the United States has not yet ratified it, and the treaty cannot fairly be read to include the human genetic material of indigenous peoples. *See Greely, supra* note 26, at 1405-06. For a discussion of international instruments addressing the issue but not binding on the United States, see *infra* Part III.B.1-2.

redress for indigenous people.<sup>138</sup> Self-determination is the most directly relevant of those rights.<sup>139</sup>

For example, Article 1 of the International Covenant on Civil and Political Rights<sup>140</sup> ("ICCPR"), an international treaty covering many human rights, proclaims that: "All peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development."<sup>141</sup> The United States signed onto the treaty in 1992.<sup>142</sup> States that have become signatories to the treaty assume the responsibility of promoting the right to self-determination.<sup>143</sup> Its effectiveness is severely limited in the United States, however, because it was ratified with several reservations, understandings, and declarations.<sup>144</sup> One of the declarations provides that Articles one through twenty-seven of the ICCPR are non-self-executing, thus requiring that Congress pass enabling legislation before the provisions can be en-

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138. *See, e.g.*, U.N. Charter art. 1, para 3 (identifying as purposes of the United Nations the promotion and encouragement of "respect for human rights and for fundamental freedoms for all"); International Convention on the Elimination of All Forms of Racial Discrimination, G.A. Res. 1904, U.N. GAOR, 18th Sess., Supp. No. 15, at 35, U.N. Doc. A/5515 (1963), 660 U.N.T.S. 195 (opened for signature Mar. 7, 1966, entered into force Jan. 4, 1969) (charging states to condemn and eliminate racial discrimination in all its forms). *But see* Jo L. Southard, *Human Rights Provisions of the U.N. Charter: The History in U.S. Courts*, 1 ILSA J. Int'l & Comp. L. 41 (1995) (explaining that although U.S. courts may be becoming more ready to apply human rights treaties, courts have declined to apply these treaties in the past, citing the political question and non-self-execution doctrines).

139. *See infra* Part III.A.

140. G.A. Res. 2200A (XXI), U.N. GAOR, 21st Sess., Supp. No. 16, at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171 (1966) (opened for signature Dec. 16, 1966, entered into force Mar. 23, 1976), S. Exec. Doc. E, 95-2, at 1 (1978) [hereinafter ICCPR].

141. *Id.* art. 1, para 1.

142. *See* 138 Cong. Rec. S4781-4784 (1992) (U.S. Senate consented to ratification on April 2, 1992); 31 I.L.M. 645, 645 (1992) (U.S. deposited ratifying instrument at the U.N. on June 8, 1992).

143. ICCPR, *supra* note 140, art. 1, para 3 ("The States Parties to the present Covenant, including those having responsibility for the administration of Non-Self-Governing and Trust Territories, shall promote the realization of the right of self-determination, and shall respect that right, in conformity with the provisions of the Charter of the United Nations.").

144. Senate Committee on Foreign Relations Report on the International Covenant on Civil and Political Rights, S. Exec. Rep. No. 23, 102 Cong., 2d Sess. 19 (1992), *reprinted in* 31 I.L.M. 645, 648-60 [hereinafter Senate ICCPR Report]; *see* Ann Fagan Ginger, *The Energizing Effect of Enforcing a Human Rights Treaty*, 42 DePaul L. Rev. 1341 (1993) (exploring how the ICCPR can be enforced despite obstacles).

forced.<sup>145</sup> Such legislation was not contemplated at the time of ratification and has not been passed.<sup>146</sup>

Treaties are not the only international law that can bind the United States. The second source of international law is customary international law.<sup>147</sup> It is created by the consistent practice of nations and adhered to out of a sense of legal obligation.<sup>148</sup> Customary international law is unwritten and is more amorphous and harder to define than codified laws but, once established, is nonetheless binding on all states, even states that disagree with the law.<sup>149</sup> The Supreme Court and U.S. circuit courts have held that customary international law is part of U.S. law.<sup>150</sup>

There is no customary international law concerning research of indigenous peoples' genetic material because the research has not been around long enough for there to be a generally accepted practice of nations in this area. Customary international law can, however,

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145. Senate ICCPR Report, *supra* note 144, at 659; *see* *Dreyfus v. Von Finck*, 534 F.2d 24, 30 (2d Cir. 1976) ("It is only when a treaty is self-executing, when it prescribes rules by which private rights may be determined, that it may be relied upon for the enforcement of such rights."); Restatement (Third), *supra* note 136, § 111(3)-(4) (identifying what makes a treaty non-self-executing and stating that non-self-executing agreements are only given legal effect by "necessary implementation"); *id.* cmt. h (providing a further explanation of non-self-executing treaties).

146. *See* Senate ICCPR Report, *supra* note 144, at 657 ("[E]xisting U.S. law generally complies with the Covenant; hence, implementing legislation is not contemplated.").

147. Restatement (Third), *supra* note 136, § 102(1)(a).

148. *Id.* § 102(3).

149. Multilateral treaties that are open to all nations are binding on those states that sign it, but can also evidence customary international law. *Id.* cmts. f & i. A state that disagrees with a developing customary international law can escape its binding effect only if it declares its dissent before the law becomes established. *See id.* § 102 cmt. b.

150. *See* *The Paquete Habana*, 175 U.S. 677, 700 (1900) (stating that, in the absence of controlling authority, a court must look to the customs and usages of nations). In *Filartiga v. Pena-Irala*, the Second Circuit recognized that customary international law grants human rights to all people. 630 F.2d 876 (2d Cir. 1980). The Filartiga family brought an action under the Alien Tort Claims Act, 28 U.S.C. § 1350 (1994), against Americo Pena-Irala for his role in the kidnapping and tortured killing of Joelito Filartiga. *Filartiga*, 630 F.2d at 878. Pena-Irala was the Inspector General of Police in Auncion, Paraguay at the time of the murder. *Id.* The family did not argue that their cause of action arose from a U.S. treaty. *See id.* at 879. Instead, the Filartigas relied on customary international law because the United States did not have a torture statute. The court pointed to U.N. documents, the practice of nations, and legal scholarship to support its conclusion that a country's torture of its citizens was a violation of the law of nations under the statute. *Id.* at 880-84. The court in *Tel-Oren v. Libyan Arab Republic*, 726 F.2d 774 (D.C. Cir. 1984), refused to expand the acts that would qualify as violations of the law of nations to include terrorism and unofficial torture. *But see* Andrew M. Scoble, Comment, *Enforcing the Customary International Law of Human Rights in Federal Court*, 74 Cal. L. Rev. 127 (1986) (discussing both *Filartiga* and *Tel-Oren* and arguing that the violations of the law of nations, covered by the Alien Tort Claims Act, should not only include customary international laws that were recognized when the statute was passed in 1789, but also those that develop later).

evolve when states consistently recognize the rights of indigenous peoples to control their genetic material out of a sense of legal obligation. When such a uniform practice is eventually established, it will constitute customary international law.

Indigenous people should not have to wait for a customary international law to develop for protection. Not only may customary international law take a long time to develop and become recognized,<sup>151</sup> but indigenous people will likely encounter resistance when attempting to enforce these rights in court because U.S. judges are often hesitant to recognize claims based on customary international law.<sup>152</sup>

This part has illustrated that neither domestic common law nor international law provide the protection that indigenous people need. The next part will demonstrate, however, that protection of indigenous peoples' ability to control their genetic material is consistent with, and advanced by, international human rights law.

### PART III. INTERNATIONAL HUMAN RIGHTS LAW REEXAMINED

Although neither domestic common law nor international human rights law adequately address indigenous concerns in this area, a human rights norm that recognizes indigenous peoples' right to con-

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151. There is no *requirement*, however, that state practice continue for a long time to establish a customary international law. *North Sea Continental Shelf Cases*, 1969 I.C.J. 3, 44-45; Restatement (Third), *supra* note 136, § 102 reporters' note 2. Although a uniform practice that qualifies as customary international law may take a while to develop, there is no legal barrier to a more immediate recognition of that law. *See id.* Thus, a customary international law recognizing indigenous peoples' right to control their genetic material could develop and become binding very quickly.

152. *See* Anne Bayefsky & Joan Fitzpatrick, *International Human Rights Law in United States Courts: A Comparative Perspective*, 14 Mich. J. Int'l L. 1, 28 (1992) (suggesting that the ambiguities of customary international law are one reason why courts often decline to use it to enforce human rights); Paul L. Hoffman, *The "Blank Stare Phenomenon": Proving Customary International Law in U.S. Courts*, 25 Ga. J. Int'l & Comp. L. 181, 182 (1995/96) ("[J]udicial skepticism is one of the largest obstacles for a lawyer trying to use customary law in domestic litigation.").

A current discussion about whether human rights should be recognized as federal common law and binding on the United States without action of the political branches of our government could prove to be another hurdle. *See* Curtis A. Bradley & Jack L. Goldsmith, *Customary International Law as Federal Common Law: A Critique of the Modern Position*, 110 Harv. L. Rev. 815 (1997) (arguing that U.S. courts should not apply customary international law unless the federal branches of the federal government authorize the application); Curtis A. Bradley & Jack L. Goldsmith, *The Current Illegitimacy of International Human Rights Litigation*, 66 Fordham L. Rev. 319 (1997) (responding to critics of their attack on customary international law as federal common law). *But see* Gerald L. Neuman, *Sense and Nonsense About Customary International Law: A Response to Professors Bradley and Goldsmith*, 66 Fordham L. Rev. 371, 379-80, 391-92 (1997) (confirming that customary international law is part of federal common law and creates binding international obligations on the United States); Beth Stephens, *The Law of Our Land: Customary International Law as Federal Law After Erie*, 66 Fordham L. Rev. 393 (1997) (defending the validity of the modern position, that it is the role of federal courts to interpret and decide whether to apply customary international law).

trol their genetic material is emerging.<sup>153</sup> This right stems from the well-accepted international human right of self-determination.

### A. *The Right to Self-Determination in the Context of Indigenous Genetic Sampling and Patenting*

Self-determination is an important human right for indigenous peoples. This part will first explore the scope of the right and conclude that it may be read broadly. This Note will then show that the right of self-determination applies to indigenous peoples' genetic material.

#### 1. Defining the Right to Self-Determination

There is no doubt that self-determination is an international human right.<sup>154</sup> There is little agreement, however, regarding its meaning and scope.<sup>155</sup> A traditional definition of the right to self-determination, often referred to as "external self-determination," developed in the context of decolonization as the group right of a people to define themselves as a separate international entity.<sup>156</sup> In this context, indigenous self-determination is often discussed as a right to complete independence from the nation in which the group is geographically

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153. See *infra* Part III.B.

154. See *supra* notes 140-41 and accompanying text; *infra* notes 161-62 and accompanying text; Hurst Hannum, *Autonomy, Sovereignty, and Self-Determination: The Accommodation of Conflicting Rights* 27 (1990) [hereinafter *Autonomy, Sovereignty, and Self-Determination*] ("Perhaps no contemporary norm of international law has been so vigorously promoted or widely accepted as the right of all peoples to self-determination."); Allan Rosas, *The Right of Self-Determination, in Economic, Social and Cultural Rights* 79, 79 (Asbjørn Eide et al. eds., 1995) (explaining the importance of the right to self-determination through the action of the U.N. Human Rights Committee); Hurst Hannum, *Rethinking Self-Determination*, 34 *Va. J. Int'l L.* 1, 31 (1993) [hereinafter *Rethinking Self-Determination*] ("[S]elf-determination has undoubtedly attained the status of a 'right' in international law."); Jennifer E. Brady, Note, *The Huaorani Tribe of Ecuador: A Study in Self-Determination for Indigenous Peoples*, 10 *Harv. Hum. Rts. J.* 291, 298 (1997) (noting that although "the international community has embraced the doctrine of self-determination," the term remains politically charged with "no clear legal definition").

155. See *Autonomy, Sovereignty, and Self-Determination, supra* note 154, at 27 (stating that the right to self-determination is not well-defined); *Rethinking Self-Determination, supra* note 154, at 2 (noting that the right to self-determination remains "vague and imprecise"); Jill McC. Watson, *Self-Determination of Peoples and Politics*, 86 *Am. Soc'y Int'l L. Proc.* 369, 369 (1992) (remarks of Frederic L. Kirgis, Jr., law professor at Washington & Lee University) ("Self-determination is one of those normative propositions that everyone agrees is part of international law. But exactly what it means is quite another matter."); Gregory H. Fox, *Self-Determination in the Post-Cold War Era: A New Internal Focus?*, 16 *Mich. J. Int'l L.* 733, 733 (1995) (reviewing Yves Beigbeder, *International Monitoring of Plebiscites, Referenda and National Elections: Self-Determination and Transition to Democracy* (1994)) ("Self-determination is a concept increasingly at war with itself.").

156. See Antonio Cassese, *Self-Determination of Peoples: A Legal Reappraisal* 67-100 (1995); Curtis G. Berkey, *International Law and Domestic Courts: Enhancing Self-Determination for Indigenous Peoples*, 5 *Harv. Hum. Rts. J.* 65, 77-78 (1992).

located—one extreme of the political autonomy spectrum.<sup>157</sup> States whose borders encompass indigenous peoples resist recognizing this version of the right because the state would be forced to relinquish control over the land and natural resources of indigenous people—its territorial integrity would be compromised.<sup>158</sup> The use of self-determination in this context, however, should not detract from the application of the right in other situations.<sup>159</sup>

Self-determination encompasses less severe—that is, less threatening to the political state—collective control rights. A broader definition of the right, “internal self-determination,” is a collective right that refers to a people’s ability to control all aspects of their lives without challenging the territorial integrity of the nation in which the indigenous group is located.<sup>160</sup> The 1960 Declaration on the Granting of Independence to Colonial Countries and Peoples<sup>161</sup> declares the right to self-determination but embodies a crucial limitation of the right. The declaration was the first U.N. document to state that “[a]ll peoples have *the right* to self-determination,”<sup>162</sup> but it goes on to add: “Any attempt aimed at the partial or total disruption of the national unity and the territorial integrity of a country is incompatible with the purposes and principles of the Charter of the United Nations.”<sup>163</sup> This articulation of the right indicates that states are more willing to acknowledge the right of self-determination when the impact on the state is limited.

The human right of self-determination is complex, yet flexible enough to be defined broadly.<sup>164</sup> The broader right of self-determination is increasingly being advocated as a means to ensure greater au-

157. See Berkey, *supra* note 156, at 79; Watson, *supra* note 155, at 391-92 (remarks of Benedict Kingsbury, law professor at Duke University).

158. See Berkey, *supra* note 156, at 80.

159. See Cassese, *supra* note 156, at 349-51; see also Gerry J. Simpson, *The Diffusion of Sovereignty: Self-Determination in the Post-Colonial Age*, 32 *Stan. J. Int'l L.* 255, 285 (1996) (explaining that the focus on classic colonialism “impoverished the principle of self-determination and denuded it of the complex underlying ideas of group participation and self-government”).

160. See Cassese, *supra* note 156, at 101-40.

161. G.A. Res. 1514, U.N. GAOR, 15th Sess., Supp. No. 16, at 66, U.N. Doc. A/4684 (1960) [hereinafter *1960 Declaration*].

162. *Id.* (emphasis added). Prior to the *1960 Declaration*, the United Nations Charter referred to self-determination, but only as a *principle*, not as a *right*. U.N. Charter art. 1, para 2 (“The Purposes of the United Nations are . . . [t]o develop friendly relations among nations based on respect for the principle of equal rights and self-determination of peoples . . .”).

163. *1960 Declaration*, *supra* note 161.

164. See Eric Kolodner, *The Future of the Right to Self-Determination*, 10 *Conn. J. Int'l L.* 153, 154 (1994) (“Rather than abandoning self-determination principles, the international community must readjust its conception of self-determination to address the changing needs of a post-Cold War world.”); Simpson, *supra* note 159, at 258 (arguing for the widening and enriching of the right to self-determination).

tonomy for indigenous peoples.<sup>165</sup> Nations are more receptive to indigenous claims of self-determination that do not entail territorial sovereignty.<sup>166</sup> The attempt to employ internal self-determination to protect interests of indigenous peoples, however, is sometimes dismissed by those who argue that self-determination is not able to support all grievances of indigenous peoples.<sup>167</sup> Those who would limit the right demand evidence that there is widespread recognition of the specific application of the broader right claimed.<sup>168</sup> The idea that the right to self-determination is already fully formed and limited to its narrow definition, however, limits a tool that could be used to combat new challenges faced by indigenous groups.<sup>169</sup> The indigenous rights fairly encompassed in self-determination only recently have been defined,<sup>170</sup> and the definition continually expands.<sup>171</sup>

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165. See Henry J. Steiner & Philip Alston, *International Human Rights in Context* 1011 (Henry J. Steiner & Philip Alston eds., 1996) (“[T]here is a developing tendency to grant certain rights, increasingly referred to as self-determination rights, to indigenous peoples.”); Berkey, *supra* note 156, at 81 (“For indigenous peoples, including American Indians, the right of self-determination is gradually becoming part of customary international law.”). Post-colonial self-determination will provide a greater range of human rights to a broader scope of peoples. See *id.* at 81 (“There are increasing signs that international law will accommodate the aspiration of indigenous peoples for self-determination.”); *Rethinking Self-Determination*, *supra* note 154; Raidza Torres, *The Rights of Indigenous Populations: The Emerging International Norm*, 16 *Yale J. Int’l L.* 127, 142 (1991); see also Kolodner, *supra* note 164, at 154 (“[T]he international community can simultaneously promote human rights and world stability only if it cautiously supports movements for external self-determination and actively encourages movements for internal self-determination.”); cf. Brady, *supra* note 154 (arguing that the Ecuadorian government should recognize the right of internal self-determination of the Huaorani, a tribe in Ecuador, allowing them to exercise greater control over their environment).

166. See Berkey, *supra* note 156, at 83; Torres, *supra* note 165, at 162; see also, Fox, *supra* note 155, at 736 (“[A]n internal conception of self-determination is slowly gaining acceptance.”); cf. Russel Lawrence Barsh, *Indigenous Peoples in the 1990s: From Object to Subject of International Law?*, 7 *Harv. Hum. Rts. J.* 33, 35-36 (1994) (noting that indigenous people may view as racist a definition of self-determination that discourages the disruption of territory because it would draw a distinction between their rights and the rights of other peoples).

167. See Watson, *supra* note 155, at 395 (remarks of William S. Grodinsky, chair-elect of the Canadian Bar Association Native Law Section) (“[P]oliticians tend to . . . simply lump any claim to sovereignty or self-determination in one big package; some even go to the extreme of ridiculing or trivializing legitimate claims.”).

168. See Anthony D’Amato, *Human Rights as Part of Customary International Law: A Plea for Change of Paradigms*, 25 *Ga. J. Int’l L.* 47, 49-50 (1995/96).

169. See S. James Anaya, *The Capacity of International Law to Advance Ethnic or Nationality Rights Claims*, 75 *Iowa L. Rev.* 837, 842 (1990) (arguing that discussion of the right must move past the absolutist terms of independent statehood “if self-determination is to be meaningful in the context of most current ethnic autonomy claims”).

170. Watson, *supra* note 155, at 394 (remarks of William S. Grodinsky, see *supra* note 167).

171. See Anaya, *supra* note 169, at 841 (“[S]elf-determination arises within international law’s expanding lexicon of human rights concerns and accordingly is posited as a fundamental right that attaches collectively to groups of living human beings.”).

## 2. Self-Determination in the Context of Indigenous Genetic Research

During United Nations negotiations over the International Covenants on Human Rights,<sup>172</sup> many nations recognized that self-determination would inevitably be defined broadly.<sup>173</sup> The right to self-determination today necessarily emerges from its history, but current formulations of it must respond to present challenges.<sup>174</sup> The government of the country that the indigenous people inhabit are not their only oppressors. Rather, as the situation of indigenous sampling and patenting illustrates, the source of the harm can be other nations and non-state entities, like corporations. The right to self-determination is flexible and could include new applications outside of the traditional context.<sup>175</sup>

The group right of an indigenous people to decide whether, and to what extent, to participate in genetic research should be recognized as within the scope of self-determination. First, heightened protection for indigenous people can be justified because they are uniquely vulnerable.<sup>176</sup> Second, indigenous peoples are being uniquely targeted for genetic research, but there is no mechanism beyond private contract to ensure that they will benefit from the research. Thus, indigenous peoples' interests are not likely to be protected through the policymaking process because their interests are at least different from, and possibly adverse to, those of who define the agenda. Further, the expanding right to self-determination supports the emerging international norm, discussed below, which recognizes indigenous peoples' right to control genetic research.

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172. The International Covenants on Human Rights include the International Covenant on Civil and Political Rights, *supra* note 140, and the International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200 (XXI), U.N. GAOR, 21st Sess., Supp. No. 16, at 49, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 3 (opened for signature Dec. 16, 1966, entered into force Jan. 3, 1976), S. Exec. Doc. D, 95-2, at 1 (1978). See Louis Henkin, *The International Bill of Rights: The Covenant on Civil and Political Rights 1* (Louis Henkin ed., 1981); Richard B. Lillich & Hurst Hannum, *International Human Rights: Problems of Law, Policy, and Practice 189-90* (1995). The Universal Declaration of Human Rights, G.A. Res. 217A(III), U.N. Doc. A/810, at 71 (1948) [hereinafter *Universal Declaration*], includes a list of human rights that was approved without dissent because it was meant to be an unenforceable, aspirational document. Henkin, *supra*, at 9-11. The International Covenants on Human Rights were drafted to give legal effect to the goals set out in the *Universal Declaration*. *Id.*

173. *Rethinking Self-Determination*, *supra* note 154, at 23-24.

174. See Olivia Q. Goldman, *Indigenous Peoples and the Right to Self-Determination*, 87 Am. Soc'y Int'l L. Proc. 190, 191 (1993) (remarks by Howard R. Berman, professor at California Western School of Law) ("History is relevant [to the problems faced by indigenous people today], but our solutions must be contemporary.").

175. See Anaya, *supra* note 169, at 842 ("[T]he concept of self-determination is capable of embracing much more nuanced interpretations and applications, particularly in an increasingly interdependent world in which the formal attributes of statehood mean less and less.").

176. For example, indigenous peoples do not speak the same language as the researchers and are not familiar with the concepts of genetics and intellectual property.

The question arises of whether the human right to self-determination is so broad as to secure the right to control one's genetic material to all people. That is, should a person like Moore prevail on a self-determination theory by virtue of his being human? Currently, the *substantive* elements of the international human right to self-determination apply to groups and individuals, but remedies based on the right are limited to groups.<sup>177</sup> This Note focuses on self-determination as a group right. Whatever the potential breadth of self-determination,<sup>178</sup> any international conceptualization of the right at least must include indigenous autonomy and consensual action.<sup>179</sup>

It is important to realize, however, that the recognition of a group right creates a tension with individual rights and the prospect of the individual dissenter.<sup>180</sup> In the context of indigenous genetic sampling and patenting, this problem could arise in at least two situations. The first is where the group decides that it does not want to participate in the research while an individual does. The other is the opposite situation, where the group wants to participate, but an individual does not want to participate. In the latter scenario, although the dissenter may not be forced to actively participate in the research by contributing her personal genetic material, researchers could learn information about her similar genetic makeup through their research on the willing group participants. In both cases the individual loses control if the

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177. See Indigenous Peoples in International Law, *supra* note 5, at 80 (“[W]hile the substantive elements of self-determination apply broadly to benefit all segments of humanity, self-determination applies more narrowly in its remedial aspect. Remedial prescriptions and mechanisms developed by the international community necessarily only benefit groups that have suffered violations of substantive self-determination.”).

178. Perhaps a person in Moore's position could successfully argue that the right to self-determination includes a general right of all individuals to control their genetic material. Even if the international human rights conceptualization of self-determination has not expanded to embrace such a claim, the domestic common law right of self-determination, generally recognized as an individual right, might apply. The term self-determination has been imbued with the idea of bodily integrity and could be applied to allow for greater control of the individual over her body. See *Cruzan v. Missouri Dep't of Health*, 497 U.S. 261, 287 (1990) (O'Connor, J., concurring) (“Because our notions of liberty are inextricably entwined with our idea of physical freedom and self-determination, the Court has often deemed state incursions into the body repugnant to the interests protected by the Due Process Clause.”).

179. See Goldman, *supra* note 174, at 192 (remarks by Berman) (“[I]ndigenous control and consent are the measure by which international action must be evaluated.”); Watson, *supra* note 155, at 394 (remarks of Grodinsky, *see supra* 167) (“[S]elf-determination’ and ‘sovereignty’—are not part of the vocabulary of native people. We tend to impose our words and concepts on them, not listening to what they have in mind with respect to self-determination and sovereignty.”).

180. This perceived tension, however, may not be as imbedded in indigenous cultures as it is in Western culture. See Robert N. Clinton, *The Rights of Indigenous Peoples as Collective Group Rights*, 32 Ariz. L. Rev. 739 (1990) (“To Native Americans, . . . group and individual rights are not antithetical concepts, they are complementary concepts.”); Iles, *supra* note 25, at 52 (“[T]he bias towards individualism ignores the complex ways in which human rights promote groups and group interaction in social life.”).

group right is permitted to trump the individual's right.<sup>181</sup> Although this conflict raises difficult policy questions, the difficulty is not a product of recognizing a right of self-determination in this context. Rather, recognizing the right would create a sphere of protection in which the conflict between group and individual interests could be negotiated within the indigenous community.

To sufficiently protect the rights of indigenous people, an attempt must be made to involve them at all levels of discussions that impact their rights. Indigenous peoples themselves can best evaluate how to formulate the right in a manner that adequately protects them.<sup>182</sup> Unfortunately, indigenous groups have been excluded from participating in some of these forums. For example, when the First International Conference on DNA Sampling was held on September 6-8, 1996, in Montreal,<sup>183</sup> it was attended mostly by academics. While billed as an open examination of the ethical, legal, and policy concerns surrounding the collection and patenting of human blood and tissue samples, indigenous groups were not invited to participate in the conference.<sup>184</sup> During the conference, indigenous rights advocates organized by Rural Advancement and Cultural Survival Canada staged a protest of the exclusion.<sup>185</sup> Indigenous voices must be heard and heeded if world policy is to possess any legitimacy.<sup>186</sup> The next part illustrates that several groups recognize indigenous peoples' right to control their genetic material.

### B. Evidence of an Emerging Norm

An international norm consists of a pattern of communication and responses given by international organizations and states to new issues that have not been in dispute long enough for a customary international law to form.<sup>187</sup> The standard for formulating a norm is less

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181. Whether the group right should be able to trump an individual right is beyond the scope of this Note. There have been no reports to date of instances where there was an individual dissenter, however. It may be that dissenters do not voice objections in their communities, or are not heard by the press. Although there has not yet been evidence of the group/individual tension, the possibility poses a serious concern nonetheless.

182. Kastrup, *supra* note 5, at 122 (arguing that indigenous self-determination must be recognized because indigenous peoples best understand their own needs).

183. Paul Weinberg, *Indigenous Groups Target "Vampire Project,"* Inter Press Service, Sept. 9, 1996, available in 1996 WL 11625270.

184. *Id.*

185. *Id.*

186. See Robert A. Williams, Jr., *Encounters on the Frontiers of International Human Rights Law: Redefining the Terms of Indigenous Peoples' Survival in the World*, 1990 Duke L.J. 660 (describing the direct participation of indigenous peoples in the drafting of the U.N. Draft Declaration on the Rights of Indigenous Peoples, discussed *infra* part III.B.1); see also Barsh, *supra* note 5, at 783-86 (describing continued indigenous participation in the process of drafting the U.N. Draft Declaration).

187. See *Indigenous Peoples in International Law*, *supra* note 5, at 50; Torres, *supra* note 165, at 145.

stringent than for a customary international law because a norm does not require identical formulations or a uniform response.<sup>188</sup> In this context, an emerging norm results when the dialogue between indigenous peoples and their advocates, state governments, international organizations, commercial actors, and academics begin to form a patterned response to a problem confronting indigenous people.<sup>189</sup> Although not binding on states, evidence of emerging norms anticipates what may develop into positive law or become recognized as customary international law. Thus, such emerging norms may eventually be binding on states. If a norm is identified as emerging, or established, the norm should positively affect state behavior.<sup>190</sup>

An international norm that recognizes the legal personality and rights of indigenous people is emerging.<sup>191</sup> A similar norm specifically addressing indigenous sampling and patenting is also emerging. A patterned response to indigenous genetic research is developing as is evidenced by documents produced by international organizations, such as the United Nations, indigenous bodies, and the research community. The organizations that have confronted this issue have uniformly concluded that genetic research, if done at all, must only be conducted with the fully informed consent of the indigenous peoples.

### 1. *U.N. Draft Declaration on the Rights of Indigenous Peoples*

The Working Group on Indigenous Populations of the Sub-Commission on Prevention of Discrimination and Protection of Minorities adopted a Draft Declaration on the Rights of Indigenous Peoples ("Draft Declaration").<sup>192</sup> Representatives from many indigenous groups were involved in the shaping of the draft by offering their views and suggestions at working group meetings.<sup>193</sup> Government representatives are now meeting about the draft in a working group of

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188. See Torres, *supra* note 165, at 145.

189. See Indigenous Peoples in International Law, *supra* note 5, at 50; Torres, *supra* note 165, at 145-46.

190. See Indigenous Peoples in International Law, *supra* note 5, at 50; Torres, *supra* note 165, at 145.

191. See Indigenous Peoples in International Law, *supra* note 5, at 49-58; see, e.g., International Labour Organisation Convention on Indigenous and Tribal Peoples, Convention No. 169 art. 7 (1989) ("The peoples concerned shall have the right to decide their own priorities for the process of development as it affects their lives, beliefs, institutions and spiritual well-being . . ."); see also Barsh, *supra* note 166 (describing the progress indigenous peoples have made in securing international recognition of their rights and legal status).

192. *U.N. Draft Declaration on the Rights of Indigenous Peoples*, U.N. Commission on Human Rights, Sub-Commission on the Prevention of Discrimination and Protection of Minorities, 46th Sess., Agenda Item 15, U.N. Doc. E/CN.4/Sub.2/1994/2/Add.1 (1994) [hereinafter *U.N. Draft Declaration*].

193. See Julian Burger, *The United Nations Draft Declaration on the Rights of Indigenous Peoples*, 9 St. Thomas L. Rev. 209 (1996) (providing an overview of the progress of the Draft Declaration).

the Commission on Human Rights.<sup>194</sup> The U.N. General Assembly wants the Draft Declaration adopted by the year 2004, the end of the Decade of Indigenous People.<sup>195</sup>

The Draft Declaration acknowledges the urgent need to recognize the rights of indigenous peoples.<sup>196</sup> Through recognition of these rights, indigenous peoples will be empowered to control and promote their development.<sup>197</sup> Article Three explicitly states that indigenous peoples have the right of self-determination.<sup>198</sup> Additionally, the Draft Declaration explicitly states that indigenous peoples' genetic resources are entitled to special protection.<sup>199</sup> The draft acknowledges that indigenous peoples are entitled to the full ownership and control of their cultural property, which specifically includes human genetic resources.<sup>200</sup> The draft further recognizes the right of indigenous peoples to protect their cultural property and obtain restitution for property taken from them without their free and informed consent.<sup>201</sup>

The International Bioethics Committee, established by the United Nations Educational, Scientific, and Cultural Organization

194. See Barsh, *supra* note 5 (detailing indigenous and state participation in the continued drafting).

195. G.A. Res. 48/163, U.N. GAOR, 48th Sess., Supp. No. 49, at 281, U.N. Doc. A/48/49 (1993).

196. *U.N. Draft Declaration, supra* note 192, at 2 ("Recognizing the urgent need to respect and promote the inherent rights and characteristics of indigenous peoples, especially their rights to their lands, territories and resources, which derive from their political, economic and social structures and from their cultures, spiritual traditions, histories and philosophies . . .").

197. *Id.* ("Convinced that control by indigenous peoples over developments affecting them and their lands, territories and resources will enable them to maintain and strengthen their institutions, cultures and traditions, and to promote their development in accordance with their aspirations and needs . . .").

198. *Id.* Part I, art. 3 ("Indigenous peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.").

199. *Id.* Part VI, art. 29.

200. Part VI, art. 29 of the *U.N. Draft Declaration* states:

Indigenous peoples are entitled to the recognition of the full ownership, control and protection of their cultural and intellectual property.

They have the right to special measures to control, develop and protect their sciences, technologies and cultural manifestations, including *human and other genetic resources*, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs and visual and performing arts.

*Id.* (emphasis added).

201. Part III, art. 12 of the *U.N. Draft Declaration* states:

Indigenous peoples have the right to practise and revitalize their cultural traditions and customs. This includes the right to maintain, protect and develop the past, present and future manifestations of their cultures, such as archaeological and historical sites, artifacts, designs, ceremonies, technologies and visual and performing arts and literature, as well as the right to the restitution of cultural, intellectual, religious and spiritual property taken without their free and informed consent or in violation of their laws, traditions and customs.

*Id.*

("UNESCO") in 1992, prepared and finalized the Revised Preliminary Draft of a Universal Declaration on the Human Genome and Human Rights.<sup>202</sup> On July 26, 1997, an intergovernmental committee adopted the draft, which will be submitted to the UNESCO General Conference for adoption this year.<sup>203</sup> The draft covers all human genome research, not just that involving indigenous peoples. The drafters recognized the vast potential benefit that human genome research might yield, but proclaim that no genetic research application should be granted to the detriment of human dignity and human rights.<sup>204</sup> Human genome research should only be conducted in accordance with law, and with the prior, free, and informed consent of the subject.<sup>205</sup> The draft calls on researchers to act with caution and integrity.<sup>206</sup> Article 16 charges nations with the responsibility to prevent abuses in genome research.<sup>207</sup> Article 19 requires all states to take "all appropriate measures" to ensure implementation of the draft's principles.<sup>208</sup>

## 2. *Indigenous Declarations*

Indigenous peoples have also addressed the issue of genetic research. A group of indigenous peoples from Asia produced the *Sabah Statement* at a regional meeting in 1995.<sup>209</sup> The participants squarely addressed the issue of genetic sampling and patenting, recognizing the practice as neocolonialism.<sup>210</sup> They also concluded that control over the indigenous peoples' genetic material was inseparable from their struggle for self-determination.<sup>211</sup> The invasive actors were identified as "transnational corporations[,] . . . institutions, researchers and scientists who are after the profits and benefits gained through monopoly control."<sup>212</sup> The statement describes the patent process as a foreign mechanism<sup>213</sup> that works "to exploit the indigenous knowl-

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202. UNESCO July 29, 1997 Release about Declaration on Human Genome and Human Rights (visited Nov. 2, 1997) <<http://www.eurekaalert.org/summaries/1120.html>>.

203. *Id.*

204. *Revised Preliminary Draft of a Universal Declaration on the Human Genome and Human Rights*, UNESCO Int'l Bioethics Comm., art. 5 (1997) [hereinafter *Human Genome Draft Declaration*].

205. *Id.* art. 6(a)-(b).

206. *Id.* art. 10.

207. *Id.* art. 16.

208. *Id.* art. 19.

209. *Sabah Statement*, *supra* note 42.

210. *See id.*

211. *See id.* ("[T]he struggle for self-determination cannot be separated from the campaign against intellectual property rights systems, particularly their applications on life forms and indigenous knowledge.").

212. *Id.*

213. *Id.* ("For the indigenous people of Asia, the intellectual property rights system is not only a very new concept but it is also very western.").

edge and resources of the indigenous peoples."<sup>214</sup> This system is unfamiliar to indigenous peoples and its use by industrialized nations engenders a reaction of frustration and resentment among indigenous peoples.<sup>215</sup>

Another regional meeting of indigenous peoples yielded the *Declaration of Indigenous Peoples of the Western Hemisphere Regarding the Human Genome Diversity Project*.<sup>216</sup> The participants believe it is the responsibility of indigenous peoples "to insure [that] the continuity of the natural order of all life is maintained for generations to come."<sup>217</sup> This end can only be achieved by respecting and not tampering with the natural order of life.<sup>218</sup> Because the indigenous representatives view genetic technology as antithetical to nature, the declaration rejects the patenting of all genetic materials.<sup>219</sup> The declaration specifically speaks out against the Diversity Project and its plan to collect indigenous genetic material.<sup>220</sup> The declaration urges the international community to develop binding agreements that similarly protect all forms of life.<sup>221</sup>

214. *Id.*

215. *Id.* ("The intellectual property rights system and the (mis)appropriation of indigenous knowledge without the prior knowledge and consent of indigenous peoples evoke feelings of anger, of being cheated, and of helplessness in knowing nothing about intellectual property rights and indigenous knowledge piracy.")

216. *Phoenix Declaration*, *supra* note 42.

217. *Id.*

218. *Id.* ("The principle of harmony requires that we do not violate the principles of Creation by manipulating and changing the natural order.")

219. The drafters of this declaration apparently would not approve of any genetic research involving indigenous peoples, notwithstanding informed consent and compensation. The declaration explains that:

In the long history of destruction which has accompanied western colonization we have come to realize that the agenda of the non-indigenous forces has been to appropriate and manipulate the natural order for the purposes of profit, power and control.

To negate the complexity of any life form by isolating and reducing it to its minute parts, western science and technologies diminishes [sic] its identity as a precious and unique life form, and alters its relationship to the natural order.

Genetic technologies which manipulate and change the fundamental core and identity of any life form is an absolute violation of these principles and creates the potential for unpredictable and therefore dangerous consequences.

Therefore, we the Indigenous Peoples participating in this meeting representing communities from North, Central and South America reject all programs involving genetic technology.

*Id.*; *see also id.* ("We hold that life cannot be bought, owned[,] sold, discovered or patented, even in its smallest form.")

220. *Id.*

221. *Id.*

### 3. *Diversity Project's Model Ethical Protocol*

The scientific community, interested in gaining access to indigenous genetic material, recognizes the need to obtain informed consent of the indigenous peoples. Consequently, the North American Regional Committee of the proposed Human Genome Diversity Project has developed the Model Protocol mentioned above.<sup>222</sup> In developing the Model Protocol, the Diversity Project considered the principles of informed consent, respect for indigenous people's culture, and adherence to international human rights standards.<sup>223</sup> The document tackles a number of difficult questions surrounding the issue of indigenous genetic sampling, including informed consent, compensation, patenting, ownership, and control.<sup>224</sup> The Model Protocol deals with the issues of informed consent in the greatest depth. Recognizing that it was demanding a requirement beyond existing law, the Diversity Project insists that consent be obtained from the relevant governments, the indigenous people as a group, and the individuals themselves.<sup>225</sup>

The documents discussed above represent responses from international governing bodies, indigenous organizations, and the scientific community. Some of the groups that have considered the issue have determined that indigenous peoples have the right to control their genetic material and that researchers must obtain an indigenous people's informed consent before involving them in research. Other groups have rejected genetic research and patenting outright. Although the conclusions are not identical, they have a common denominator. Indeed, an international norm is emerging—that the indigenous peoples themselves must control whether and to what extent to participate in genetic research. The U.S. government itself has begun to participate in advancing the norm as was evidenced by its decision to withdraw the Guaymi patent.<sup>226</sup> This Note now argues that the United States should strengthen its support of human rights by passing legislation acknowledging the right of indigenous peoples to control their genetic material and creating causes of action for meaningful enforcement of that right.

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222. See *supra* notes 27, 35-41 and accompanying text.

223. See *Model Protocol*, *supra* note 27, at 1436.

224. See *supra* notes 36-40 and accompanying text.

225. *Model Protocol*, *supra* note 27, at 1437.

226. See *supra* note 83 and accompanying text; see also *Indigenous Peoples in International Law*, *supra* note 5, at 50 (“[C]onforming conduct will strengthen emergent customary rules by enhancing attendant subjectivities of expectation.”).

PART IV. THE UNITED STATES SHOULD RECOGNIZE THE  
EMERGING HUMAN RIGHTS NORM

Research groups, drug companies, and governments have been operating in a virtual legal and ethical vacuum.<sup>227</sup> As discussed above, no positive law instruments exist that directly address genetic sampling and patenting.<sup>228</sup> In addition, no clear duty arises from customary international law because indigenous genetic sampling and patenting has not been practiced long enough for a widespread practice to exist.<sup>229</sup>

As established above, however, the human right to self-determination is broad and should be recognized as encompassing an indigenous people's absolute right to decide whether to participate in genetic research.<sup>230</sup> An emerging international norm also exists which recognizes that any indigenous genetic research and patenting should only be done with an indigenous people's informed consent.<sup>231</sup> The documents that international and indigenous governing bodies and the scientific community have created and continue to draft evidence an emerging norm that is gaining widespread acceptance.<sup>232</sup> It may only be a matter of time before a more formal customary international law develops.

This part argues that Congress should pass legislation recognizing indigenous peoples' absolute right to decide whether to participate in genetic research.<sup>233</sup> This legislation would create causes of action, for both injunctive relief and compensatory damages, where indigenous peoples' genetic material is used without their fully informed consent,

227. See Michael J. Malinowski & Maureen A. O'Rourke, *A False Start? The Impact of Federal Policy on the Genotechnology Industry*, 13 *Yale J. on Reg.* 163, 248 (1996) ("The gap between genotechnologies and the regulatory infrastructure bearing upon the introduction and uses of genotechnologies has broadened.").

228. See *supra* notes 136-46 and accompanying text.

229. See *supra* notes 147-52 and accompanying text.

230. See *supra* Part III.A.

231. See *supra* Part III.B.

232. See *supra* notes 192-225 and accompanying text.

233. Some groups have called for a moratorium on indigenous genetic research. See *supra* note 63; *Moratorium Sought on DNA Sampling*, *supra* note 26; see also *Final Statement from the UNDP Consultation on Indigenous Peoples' Knowledge and Intellectual Property Rights*, Suva, Fiji, April 1995 (visited Nov. 2, 1997) <<http://users.ox.ac.uk/~wgtrr/suva.htm>> ("Call[ing] for a moratorium on bioprospecting in the Pacific and urg[ing] indigenous peoples not to co-operate in bioprospecting activities until appropriate protection mechanisms are in place."); *Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples*, Whakatane, New Zealand, June 12-18, 1993 (visited Nov. 2, 1997) <<http://users/ox.ac.uk/~wgtrr/mataatua.htm>> ("A moratorium on any further commercialisation of indigenous medicinal plants and human genetic materials must be declared until indigenous communities have developed appropriate protection mechanisms."). Restrictions must be developed immediately to protect indigenous peoples before comprehensive legal safeguards are available. Any protective prohibition, however, must allow for the continued participation of groups like the Sandy Lake Band, *supra* note 72, who are fully informed and are participating in the research to benefit their community.

and adequate compensation.<sup>234</sup> To ensure protection for indigenous peoples who have only had contact with researchers, as was the case with hypothetical Groups Two and Three, the statute must impose a duty to fully inform research subjects on those scientists, researchers, companies, organization, or governments that conduct, control, fund, or contract for the benefits of indigenous genetic research. To further ensure that all indigenous peoples receive the maximum coverage, the statute must recognize a property right in their genetic material. Congress must act to prevent neocolonialism and to advance global human rights.

#### A. Congress Must Act to Avoid Neocolonialism

The relationship between indigenous populations and the dominant cultures today is structurally similar to colonialism.<sup>235</sup> European colonizers employed theories and concepts to legitimize their control over remote territories and peoples.<sup>236</sup> History is replete with examples of

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234. The Genetic Privacy Act would recognize a genetic source's property right in individually identifiable DNA. Genetic Privacy Act, § 104(a) (1995) (drafted by George J. Annas et al.) (visited Nov. 2, 1997) <<http://www-busph.bu.edu/Depts/LW/GPA/GPA.htm>>; see also Michael M.J. Lin, *Conferring a Federal Property Right in Genetic Material: Stepping into the Future with the Genetic Privacy Act*, 22 Am. J.L. & Med. 109 (1996) (comparing the Genetic Privacy Act to proposed state and federal legislation, and arguing for the Genetic Privacy Act). This proposed legislation would not, however, adequately address the unique issues surrounding indigenous genetic research, for example, traditional or group consent and neocolonialism.

235. See Goldman, *supra* note 174, at 190 (remarks by Berman, see *supra* note 174) (noting that indigenous peoples were the first victims of colonialism and continue to be its victims today). For one definition of colonialism, see Jürgen Osterhammel's Colonialism: A Theoretical Overview:

*Colonialism* is a relationship of domination between an indigenous (or forcibly imported) majority and a minority of foreign invaders. The fundamental decisions affecting the lives of the colonized people are made and implemented by the colonial rulers in pursuit of interests that are often defined in a distant metropolis. Rejecting cultural compromises with the colonized population, the colonizers are convinced of their own superiority and of their ordained mandate to rule.

Jürgen Osterhammel, *Colonialism: A Theoretical Overview* 16-17 (1997) (emphasis in original). Osterhammel also notes that colonialism is "not just any relationship between masters and servants, but one in which an entire society is robbed of its historical line of development, *externally manipulated* and transformed according to the needs and interests of the colonial rulers." *Id.* at 15 (emphasis in original).

236. For example, during classical colonialism, prior occupancy by indigenous populations "was commonly thought not to matter." Jesse Dukeminier & James E. Krier, *Property* 12 (3d ed. 1993); see Goldman, *supra* note 174, at 190 (remarks by Berman, see *supra* note 174) (pointing to "the right of discovery," "terra nullius," and the "standard of civilization"); see, e.g., *Johnson v. McIntosh*, 21 U.S. (8 Wheat.) 543 (1823) (affirming U.S. title to land previously inhabited solely by the native population based on concepts of discovery, conquest, and labor theory); see also, Williams, *supra* note 186, at 672-76 (discussing the doctrine of discovery and its impact on indigenous rights). But see W. Michael Reisman, Editorial Comment, *Protecting Indigenous Rights in International Adjudication*, 89 Am. J. Int'l L. 350 (1995) (arguing that the theories used to exercise dominance of indigenous peoples should be called into question and brought in line with contemporary international law to protect the inter-

industrialized nations appropriating the resources of indigenous populations for their own gain.<sup>237</sup> Indigenous groups were, and continue to be, vulnerable without the power to influence major decisions that impact their lives. Neocolonialism is the indirect economic and cultural dominance of one nation over a people, even when the dominant nation does not have direct control over the government of the subordinate people.<sup>238</sup>

Even though genetic sampling and patenting is considered acceptable in the United States, the practice smacks of neocolonialism when it involves indigenous peoples.<sup>239</sup> Some indigenous people are worried that, without a legal framework in place, they will be exploited

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ests of indigenous peoples); *cf.* Berkey, *supra* note 156 (arguing that the emerging international norm of self-determination should inform interpretation of domestic law and that U.S. courts should recognize a more expansive view of Native American self-government).

237. Outsiders, for example, have attempted to convince the Guaymi to cooperate with plans to acquire their natural resources. In the 1970s, one of the world's largest copper deposits was found in Panama. Chris N. Gjording, *Conditions Not of Their Choosing: The Guaymí Indians and Mining Multinationals in Panama* ix (George Vranas & Peter Johnson eds., 1991). The discovery prompted the interest of multinational mining firms. *Id.* at 3. Debate about the project included the Panamanian government, the mining companies, and major Panamanian business associations, but ignored the views of the Guaymi. In response to the proposed project, the Guaymi Congress stated that, "the Guaymí people want progress and development but not in the form that the State . . . wants to impose, via huge projects that guarantee no real benefit and which only proceed in detriment of the Guaymí people toying with them via promises." *Id.* at 5 (quoting *Congresos Guaymies* 1980:48).

238. See Robert W. Tucker, *The Inequality of Nations* 68 (1977); see, e.g., Naomi Roht-Arriaza, *Of Seeds and Shamans: The Appropriation of the Scientific and Technical Knowledge of Indigenous and Local Communities*, 17 *Mich. J. Int'l L.* 919 (1996) (describing the appropriation of indigenous knowledge by the biotechnology, pharmaceutical, and agribusiness industries, universities, seed and gene banks, and research centers; suggesting possible frameworks for ending the appropriation); see also William H. Blanchard, *Neocolonialism American Style, 1960-2000*, at 5 (1996) (characterizing sustained intervention on the part of the United States and the "slow development of a long-term relationship of dominance over another nation" as neocolonialism); Stephen Roskamm Shalom, *The United States and the Philippines: A Study of Neocolonialism* xiv-xv (1981) (offering a definition of neocolonialism that parallels colonialism because, in both cases, the dominant classes of two nations create an alliance by which they can both maintain dominance over the weaker nation's population).

239. Debra Harry, a Pauite Indian from Nevada and a leading advocate for indigenous peoples stated: "Now it's colonialism on the molecular level. . . . For us, genes are our ancestry, our heredity and our future generations. They are not to be tampered with." Horvitz, *supra* note 65. Aroha Mead is a lobbyist with the Maori Congress, who has served with the government's Health Research Council and also organized a United Nations conference on indigenous intellectual property rights. She stated: "This is like slavery in a high-tech science world . . . . You are taking the lifeblood of individuals and asserting ownership. It is bad enough that you do it to your own citizens, but much worse to do it to people of other countries." Roger Highfield, *'Biopiracy' Claim After Patent on Blood Cell*, *Daily Telegraph*, Feb. 13, 1996, at 15, available in LEXIS, Nexis Library, Papers File.

for their genetic material.<sup>240</sup> Others have concerns that the unfamiliar intellectual property system will be used to harm them.<sup>241</sup> One commentator noted that the industrialized nations now interested in using indigenous peoples to advance their goals have long ignored difficult problems facing indigenous groups.<sup>242</sup>

In 1960, the U.N. General Assembly adopted the Declaration on the Granting of Independence to Colonial Countries and Peoples.<sup>243</sup> The declaration's drafters were "[a]ware of the *increasing conflicts* resulting from the denial of or impediments in the way of the freedom of such peoples, which constitute a serious threat to world peace."<sup>244</sup> The drafters had an expansive view of the forms undesirable colonialism could take.<sup>245</sup> The declaration demands the immediate end to domination of peoples and a transfer of power to them.<sup>246</sup> The General Assembly Declaration is evidence of customary international law, which would bind the United States to end all forms of colonialism.<sup>247</sup> To comply with the declaration and prevent U.S. entities from engaging in neocolonialism, Congress must pass legislation that provides redress for indigenous peoples and stiff sanctions for offenders.

### B. *Policy Supports Congressional Action*

Other important factors should motivate congressional action. Such legislation would capitalize on an excellent opportunity to lead the world by example and increase the United States' ability to advance

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240. The Third World is wary because "[w]ithout a clear legal framework forcing drug multinationals to share the wealth, they worry that the companies will abscond with both the blueprint for their 'biodiversity' and its rewards." Neil Gross & John Carey, *Who Owns the Tree of Life?*, Bus. Wk., Nov. 4, 1996, at 194, 197. Leonora Zalabta of the Arhuaco people of Colombia said, "[t]his could be another form of exploitation, only this time they are using us as raw materials." *Patenting Indigenous People*, *supra* note 42.

241. *COICA Statement*, *supra* note 135, ("The prevailing intellectual property systems must be prevented from robbing us, through monopoly rights, of resources and knowledge in order to enrich themselves and build up power opposed to our own."); *Sabah Statement*, *supra* note 42 ("The prevailing intellectual property rights system is seen as a new form of colonization and a tactic by the industrialized countries of the North to confuse and to divert the struggle of indigenous peoples from their rights to land and resources on, above and under it.").

242. Alan Swedlund, University of Massachusetts anthropology department head, charges that the project managers "want to swoop in, collect blood for their own scientific goals and then leave people to their fate." Horvitz, *supra* note 65.

243. G.A. Res. 1514 (XV), U.N. GAOR, 15th Sess., Supp. No. 16, at 66, U.N. Doc. A/4684 (1960), *supra* note 161.

244. *Id.* (second emphasis added).

245. *Id.* ("[T]he peoples of the world ardently desire the end of colonialism in *all its manifestations*." (emphasis added)).

246. *Id.* ("Immediate steps shall be taken . . . to transfer all powers to the peoples . . . in order to enable them to enjoy complete independence and freedom.").

247. *See Military and Paramilitary Activities (Nicar. v. United States)*, 1986 I.C.J. 14 (June 27) (recognizing a U.N. General Assembly Resolution as evidence of customary international law).

worldwide recognition of human rights. Even though all of the patenting nations have not yet decided to recognize claims of indigenous peoples who have grievances stemming from use of their genetic material, the United States, as a world leader, is uniquely situated to do so. Moreover, the United States has a responsibility to force dialogue and encourage action in this area.<sup>248</sup> Such a response would be in keeping with past U.S. policy and would encourage the development of human rights.<sup>249</sup> Other nations will more readily accept indigenous peoples' claims once the wall of state inaction is breached by a cornerstone. Congressional action would enable indigenous peoples' right to control their genetic material to become customary international law sooner and, as a result, the right would be binding on all states. Indeed, action by the United States would itself be considered further evidence of the emerging norm to protect the right of indigenous peoples to control their genetic material.

Furthermore, congressional action will give the United States more leverage when demanding that other nations improve their human rights records. The United States will demonstrate its concern about the rights of indigenous peoples to the rest of the world. An improvement in U.S. policy in this arena is sorely needed. For example, a London paper ran a highly unfavorable story about the Hagahai patent entitled "U.S. Slaps Patent on Tribesman's DNA."<sup>250</sup> U.S. calls for other countries to improve their human rights records will be less effective when the international community has this image of U.S. human rights policy.<sup>251</sup> By passing legislation now that provides protection for indigenous peoples, the United States can generate favorable publicity that will lend credence to U.S. requests for recognition and respect of international human rights.<sup>252</sup>

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248. See Warren Christopher, *Commemorating Human Rights Day*, U.S. Dep't St. Dispatch, Dec. 16, 1996, at 607 ("[U.S.] commitment to human rights . . . is a responsibility that comes with our leadership in the world, and a quality that strengthens our ability to lead.").

249. See Michael Scaperlanda, *Polishing the Tarnished Golden Door*, 1993 Wis. L. Rev. 965, 1020-21. Much of U.S. policy has been aimed at attempting to improve human rights in other countries. See, e.g., Christopher, *supra* note 248, at 607 (stating that defense of human rights is a fundamental interest in which he had insisted that foreign policy be grounded); White House Press Release, A Proclamation by President Clinton, Dec. 10, 1996 ("[T]he championing of democracy and human rights serves as a cornerstone of my Administration's foreign policy."); White House Press Release, Statement by the Press Secretary, Apr. 15, 1997 ("By taking a stand against human rights abuses in China and around the world, we keep faith with those who champion these principles. We also maintain our leadership on human rights issues and express the deepest values of the American people.").

250. Geoffrey Lean & Tom Wilkie, *U.S. Slaps Patent on Tribesman's DNA*, Independent, Nov. 19, 1995, at 1.

251. See, e.g., Christopher, *supra* note 248, at 608 (discussing diplomatic efforts to promote human rights in China, Cuba, Burma, and Nigeria).

252. *Id.* ("The United States is still looked at around the world as the beacon of freedom, and what we say means a great deal. What America says and does always matters.").

One of the reasons for conducting research on indigenous genome is for scientists to possibly develop a product to prevent or cure disease. If Congress fails to act, and indigenous peoples continue to be taken advantage of, eventually they will collectively decide to withhold all cooperation with genetic research. The international community must impose stringent guidelines for genetic research and provide meaningful remedies if it wants to maintain access to the potential benefits of indigenous genome. These sanctions must not only attempt to reimburse the victims, but to act as strong deterrents to abusive researchers.<sup>253</sup>

Should Congress pass legislation to protect indigenous people, it would not be the first time it acted to advance the nation's human rights goals.<sup>254</sup> In 1986, Congress passed the Comprehensive Anti-Apartheid Act (the "Act") over a presidential veto.<sup>255</sup> The Act prohibited certain commercial transactions between U.S. firms and the South African government and businesses. For example, it prohibited loans to the South African government or institutions controlled by the government<sup>256</sup> and prohibited new investment in the country by U.S. nationals.<sup>257</sup> The Act also prohibited the export of several goods to South Africa,<sup>258</sup> and the import of many South African goods into the United States.<sup>259</sup> In addition, Congress put some teeth into the legislation by passing the Rangel Amendment<sup>260</sup> which was a change in the tax law that effectively doubled the tax paid by U.S. corporations on income earned in South Africa—making it extremely expensive to do business in South Africa. The economic sanctions aimed at the South African government succeeded both in advancing human rights goals and eventually aided in toppling the apartheid regime.<sup>261</sup>

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253. See, e.g., Susan M. Kuzma, *Criminal Liability for Misconduct in Scientific Research*, 25 U. Mich. J.L. Reform 357 (arguing that criminal sanctions should be imposed against researchers for scientific misconduct).

254. See American Indian Religious Freedom Act, Pub. L. No. 95-341, 92 Stat. 469 (1978) (codified at 42 U.S.C. 1996 (1994)) (declaring the "policy of the United States to protect and preserve for American Indians their inherent right of freedom to believe, express, and exercise the traditional religions"); see also Foreign Assistance Act of 1961, 22 U.S.C. § 2151(n) (1994) (withholding assistance from countries that engages in gross human rights violations); *id.* § 2301 (1994) (withholding security assistance from countries that engages in gross human rights violations).

255. Pub. L. No. 99-440, 100 Stat. 1086 (1986) (codified at 22 U.S.C. § 5001 (1994)) [hereinafter Anti-Apartheid Act].

256. *Id.* § 5055.

257. *Id.* § 5060.

258. See, e.g., *id.* § 5054 (computers); *id.* § 5071 (petroleum goods).

259. See, e.g., *id.* § 5059(A) (uranium, textiles, and coal); *id.* § 5069, 5070 (iron, steel, and agricultural products).

260. Omnibus Budget Reconciliation Act of 1987, § 10,231, 26 U.S.C. § 901(j) (1988).

261. See Audie Klotz, *Norms in International Relations: The Struggle Against Apartheid* 151-64 (1995); cf. Richard L. Abel, *Politics By Other Means: Law in the Struggle Against Apartheid, 1980-1994* (1995) (analyzing the relationship between apartheid and South African law and politics).

If the United States takes the lead by passing legislation in this instance, it will promote an emerging human rights norm and thereby demonstrate strengthened U.S. commitment to human rights.

#### CONCLUSION

Sometimes it is less challenging to pay nominal homage to current formulations of human rights to recast them to fit the modern variations of traditional violations.<sup>262</sup> The current conceptualization of human rights must develop because it does not adequately protect indigenous peoples who are frequently harmed in the process of modernization.<sup>263</sup> Although it is less important to identify the basis for enhanced protection to "legitimize" a right, finding equitable solutions that make a difference in people's lives must be the goal. Congress can make that difference by protecting the rights of indigenous people while helping to keep responsible and fair genetic research viable. The United States has a powerful position in world politics and this is a perfect opportunity for it to bring the recognition of human rights into the next century.

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262. See Goldman, *supra* note 174, at 199 (remarks by Richard A. Falk, Center of International Studies, Princeton University. *But see Rethinking Self-Determination*, *supra* note 154, at 66-67 ("The content of self-determination, like international law, is in constant evolution . . . [and] definitions may change," but "redefining 'self-determination' may be more politically acceptable than attempting to bury it.")).

263. See *Rethinking Self-Determination*, *supra* note 154, at 68.

**DEDICATION**  
**THE NEW YORK COURT OF APPEALS: 150 YEARS**



The 1997 New York Court of Appeals (left to right): Judge Carmen Beauchamp Ciparick, Judge George Bundy Smith, Judge Vito J. Titone, Chief Judge Judith S. Kaye, Judge Joseph W. Bellacosa, Judge Howard A. Levine, Judge Richard C. Wesley.

*Notes & Observations*