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INTRODUCTION: THE BODY, ECONOMIC POWER AND SOCIAL CONTROL

DOROTHY NELKIN AND LORI B. ANDREWS*

A pregnant woman with a bar code on her belly demonstrates against the commercialization of human cord blood.¹ A patient sues his physician for patenting a cell line made from his biopsied tissue.² Two U.S. Marines are court martialed when they refuse to obey an order to give DNA to an Armed Forces physician in case it was later needed to identify their remains.³ The U.S. Centers for Disease Control have been challenged in a dispute over whether geneticists can have access, without consent, to 50,000 stored tissue samples they wish to use for their research.⁴ The body is a site of growing struggles.

The collection and use of human body tissue—from eighteenth century practices of dissection to twentieth century organ transplantation—have evoked concerns about the use of body parts without consent; the psychological, social and religious impact of deconstructing and undermining the integrity of the body; and, especially, the potential exploitation of the individuals who serve as the sources of organs and tissues. Physicians and scientists have been accused of profiteering, insensitivity to the emotions of patients or family members, and secrecy about unseemly practices as they have sought out cadavers and body parts.

Recent disputes—over the taking of body tissue,⁵ the genetic testing of previously-collected samples,⁶ the development of products

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1. See Interview with Helena Paul, Gaia Foundation, in London (June 1997).

2. See generally *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479 (Cal. 1990), *cert. denied*, 499 U.S. 936 (1991).

3. See generally Susan Essoyan, *Two Marines Challenge Pentagon Order to Give DNA Samples*, L.A. TIMES, Dec. 27, 1995, at A5, A5.

4. See generally Ellen Wright Clayton et al., *Informed Consent for Genetic Research on Stored Tissue Samples*, 274 JAMA 1786 (1995).

5. See generally, *Mayfield v. Dalton*, 109 F.3d 1423 (9th Cir. 1997).

6. See, e.g., *Clayton et al.*, *supra* note 4, at 1786, 1791. See generally *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260 (9th Cir. 1998).

made of body tissue,⁷ the patentability of human genes⁸ and the distribution of tissue⁹—raise important questions about the social and legal status of the body. This symposium explores what the body means to individuals, social groups, researchers and biotechnology companies. It reveals a common practice of taking people's tissues without their consent and documents the ways in which the law attempts to infuse social meaning into decisions about the use of body tissue. Increasingly, judges are being asked to mediate conflicts involving body tissue. By bringing together perspectives on the personal, religious and political significance of the body from the vantage points of anthropology, political science, history, sociology and ethics, we hope to help inform legal decisions about body tissue.

I. THE GROWTH OF INTEREST IN HUMAN TISSUE

Human tissue has always provided clues to health status. But the body in the biotechnology age is speaking in new ways. Scientists daily report their discoveries of genes for traits and disorders ranging from homosexuality to manic depression, from colon cancer to shyness, from Alzheimer's disease to a tendency to take risks.¹⁰ Tissue such as hair, blood or saliva, when subject to DNA analysis, can reveal intimate and detailed information about a person. Genetic testing can indicate not only an individual's future health—information that may open beneficial therapeutic or remedial options—but also the possibility of employment or insurance discrimination.¹¹ And, according to recent scientific claims, human tissue can reveal information about behavioral traits,¹² race¹³ or sexual preference.¹⁴

7. See generally, e.g., Moore, 793 P.2d 479.

8. See generally, e.g., Rebecca S. Eisenberg, *Patenting the Human Genome*, 39 EMORY L.J. 721 (1990).

9. See, e.g., Pete Mitchell, *European Researchers Condemn US Firm's Cord-Blood-Storage Patent*, 349 LANCET 1232, 1232 (1997).

10. See generally DOROTHY NELKIN & M. SUSAN LINDEE, *THE DNA MYSTIQUE: THE GENE AS A CULTURAL ICON* (1995).

11. See DOROTHY NELKIN & LAURENCE TANCREDI, *DANGEROUS DIAGNOSTICS: THE SOCIAL POWER OF BIOLOGICAL INFORMATION* 4, 7 (1989). See generally NEIL A. HOLTZMAN, *PROCEED WITH CAUTION: PREDICTING GENETIC RISKS IN THE RECOMBINANT DNA ERA* (1989).

12. See Katrina Kelner & John Benditt, *Genes and Behavior*, 264 SCIENCE 1685, 1685 (1994).

13. See Gail Vines, *Genes in Black and White*, NEW SCIENTIST, July 8, 1995, at 34, 34.

14. See generally DEAN HAMER & PETER COPELAND, *THE SCIENCE OF DESIRE: THE SEARCH FOR THE GAY GENE AND THE BIOLOGY OF BEHAVIOR* (1994).

Beyond its value as a source of information, human tissue has also become a source of raw material for products such as cell lines and diagnostic tests. The market for skin, blood, placenta, gametes, biopsied tissue and genetic material is expanding,¹⁵ driven in part by commercial incentives fostered by legal developments in the 1980s. A 1980 U.S. federal law allowed universities and nonprofit institutions to apply for patents on government-supported projects and provided tax-incentives to companies investing in academic research.¹⁶ Another law encouraged government researchers to enter into joint ventures with for-profit companies.¹⁷ At the same time, a landmark U.S. Supreme Court decision in 1980 granted a patent on a life form—a bacteria—setting the stage for the patenting of human genes.¹⁸

As John Murray notes in this symposium, patents have now been filed on more than 500,000 partial gene sequences and over 1500 patents have been granted for complete genes. Moreover, there are multiple patents affecting particular single genes.¹⁹ Numerous groups have patented variants of the breast cancer gene, and patent applications are pending for additional mutations.²⁰ This practice raises concerns among some commentators who fear that too many patents related to a single gene may actually impede useful research since it will be difficult (and costly) for a researcher to gain licenses from each patent holder.²¹ Murray examines the arguments for and against patenting human genes.

Political scientist Sheldon Krimsky looks at the ways in which patenting is influencing how researchers view each other and the institutions within which they work.²² He documents the growing commercial interests of scientists involved in the biotechnology business,²³ reviewing the history of industry-university liaisons and the legislative basis of the rapid commercialization of molecular

15. See generally ANDREW KIMBRELL, *THE HUMAN BODY SHOP: THE ENGINEERING AND MARKETING OF LIFE* (1993).

16. See generally 15 U.S.C. §§ 3701-3717 (1994 & Supp. III 1997).

17. See *id.* § 287n.

18. See *Diamond v. Chakrabarty*, 447 U.S. 303 (1980).

19. See John Murray, Note, *Owning Genes: Disputes Involving DNA Sequence Patents*, 75 CHI.-KENT L. REV. 231, 233-35 (1999).

20. See *id.*

21. See *id.* at 254.

22. Sheldon Krimsky, *The Profit of Scientific Discovery and Its Normative Implications*, 75 CHI.-KENT L. REV. 15, 28-35 (1999).

23. *Id.* at 27-28.

genetics.²⁴ Krimsky looks critically at the consequences of scientists becoming a part of the commercial sector with financial as well as professional stakes in their research.²⁵ He questions whether such changes, eroding the normative basis of scientific research, will in the long run yield a greater public benefit.²⁶

As commercial interest in body tissue increases (and is sanctioned through patent law), the social meaning of the body is sometimes ignored. Yet personal and social views of the body serve important functions for individuals and their communities. A person's control over what is done to his or her body—or its parts—is important to the individual's psychological development and well-being. It is a means to establish identity and convey values to others. Body tissue also has social importance beyond the individual.²⁷ Social concepts of the body establish community identification, encourage socially-responsible behaviors and set acceptable priorities for group activities.

Developmental psychologists have written a great deal about the formation of body image. Reviewing this complex literature, psychologist Daniel Stern found a consistent theme—the critical importance of coherence and bodily integrity to a person's development and sense of self.²⁸ To be healthy psychologically, an individual needs to experience self-agency (the ability to control what is done to one's body) and self-coherence (the ability to maintain the body as a nonfragmented, integrated whole).

Because the body is a means to express personal values, some people want to place limits on the use of their body parts. Some men who donate sperm only want it used by married couples rather than single women.²⁹ Some women will serve as a surrogate mother for women with infertility problems but not for those who want to avoid pregnancy for career reasons.³⁰ During the Nazi occupation of the

24. *Id.* at 18-22.

25. *Id.*

26. *See id.* at 39.

27. *Cf.* MARY DOUGLAS, *PURITY AND DANGER: AN ANALYSIS OF THE CONCEPTS OF POLLUTION AND TABOO* (reprinted 1989) (1966) (discussing the relationship between rituals of purity and cleansing and a sense of being or "unity in experience").

28. DANIEL N. STERN, *THE INTERPERSONAL WORLD OF THE INFANT: A VIEW FROM PSYCHOANALYSIS AND DEVELOPMENTAL PSYCHOLOGY* (1985).

29. *See generally* Lori Andrews & Dorothy Nelkin, *Whose Body Is It Anyway? Disputes over Body Tissue in a Biotechnology Age*, 35 *LANCET* 53 (1998).

30. *See generally* LORI ANDREWS, *BETWEEN STRANGERS: SURROGATE MOTHERS, EXPECTANT FATHERS, AND BRAVE NEW BABIES* (1989).

Netherlands, many citizens, as a form of social protest, refused to participate in blood transfusions for Nazi soldiers.³¹ Some African-American women, recalling past research abuses, refuse to allow amniotic tissue to be collected for prenatal diagnosis out of concern about the other uses that could be made of this tissue.³² Other people object to the use of their tissue in the commercialized setting of biotechnology firms.³³ John C. Mayfield and Joseph Vlacovsky, U.S. Marines, refused to provide DNA to the military for its mandatory DNA testing program (intended as a way to identify bodies killed in war), and were court-martialed for noncompliance.³⁴ One of their reasons for refusal was the “possible abuse of the information contained in their DNA—from job or health insurance discrimination on the basis of genetic traits to use of their samples without their consent by medical researchers or the FBI.”³⁵ Decisions people make about the body and its parts convey important messages about their individual identities, personal values, and political interests.

In this volume, Deborah Pergament explores, historically and cross culturally, the complex social meanings of a specific body tissue—hair.³⁶ She suggests that just because hair is a regenerable body part does not mean it has no social or individual importance.³⁷ Hair has importance for human dignity, for group identification, and for status. Rituals, styles, and artifacts involving human hair suggest its social meaning. The importance of hair as a cultural object arises in the context of disputes over its commercialization and over the use of hair for purposes of social control. Pergament examines how courts often ignore the personal and social meaning of hair in cases dealing with restrictions on hair appearance in schools, workplaces, prisons, and the military.³⁸ The social meaning of hair is an issue

31. See Dorothy Nelkin, *Cultural Perspectives on Blood*, in *BLOOD FEUDS: AIDS, BLOOD, AND THE POLITICS OF MEDICAL DISASTER* 273, 278 (Eric A. Feldman & Ronald Bayer eds., 1999).

32. See generally Rayna Rapp, *Refusing Prenatal Diagnosis: The Meanings of Bioscience in a Multicultural World*, 23 *SCI. TECH. & HUM. VALUES* 45 (1998) (exploring the reasons that women of different backgrounds reject prenatal diagnosis).

33. See generally Declan Butler, *French Geneticists Split over Terms of Commercial Use of DNA Bank*, 368 *NATURE* 175 (1994).

34. See *Mayfield v. Dalton*, 901 F. Supp. 300, 302 (D. Haw. 1995), *vacated*, 109 F.3d 1423 (9th Cir. 1997).

35. Susan Essoyan, *Two Marines Challenge Pentagon Order to Give DNA Samples*, *L.A. TIMES*, Dec. 27, 1995, at A5.

36. Deborah Pergament, *It's Not Just Hair: Historical and Cultural Considerations for an Emerging Technology*, 75 *CHI.-KENT L. REV.* 41, 41-42 (1999).

37. See *id.* at 43-44.

38. *Id.* at 52-58.

today as courts are increasingly involved in cases where hair analysis is used to identify potential criminal offenders and discover drug use.³⁹

DNA analysis of body tissue is a means of social control in the arena of law enforcement. The FBI and police are building DNA databases by widely collecting blood and tissue samples from individuals that can be used to match DNA found at crime scenes.⁴⁰ Bioethicist Eric Juengst reviews debates over how DNA data is collected, focussing in particular on the use of racial groups as reference categories to assess DNA matches.⁴¹ Using socially-defined categories has implications for both personal privacy and the well being of racial groups. Juengst points out that unlike traditional fingerprinting, DNA “fingerprinting” can reveal a person’s health status and other sensitive information.⁴² And he shows how racial categorization through DNA can lead to further stigmatization.⁴³ Emphasizing the dangers of using DNA identification to categorize people racially, he argues that population groups should not be used as reference classes.⁴⁴

Beyond the individual, body tissue has significant social meaning. In some Third World societies, blood, hair and placenta are important in social rituals, defining community identification and reinforcing the values and rules that govern accepted behavior.⁴⁵ But even in contemporary Western societies, the treatment of body parts can define community and reinforce social values. People signal their identification with their community by the way they display and manipulate their body—from the distinctive hair styles of African Americans or Orthodox Jews to the symbols tattooed on the arms of the Aryan Brotherhood. Sensitive questions emerge when genetic analysis of body tissue is used to reveal community identity. Through tissue analysis, a person may (whether that person wishes to or not) be identified according to particular genetic criteria as a member of a

39. *See id.* at 57-58.

40. *See* Eric T. Juengst, *I-DNA-fication, Personal Privacy, and Social Justice*, 75 CHI.-KENT L. REV. 61, 61 (1999).

41. *Id.* at 63-64.

42. *Id.* at 64.

43. *See id.* at 75-77.

44. *See id.* at 77.

45. *See generally* VICTOR TURNER, *THE FOREST OF SYMBOLS: ASPECTS OF NDEMBU RITUAL* (1967) (exploring various aspects of the ritual system of the Ndembu people); Rodney Needham, *Blood, Thunder and Mockery of Animals*, 14 SOCIOLOGUS 136 (1964) (exploring a blood sacrifice ritual that was common among certain tribes).

certain family, a certain race, a certain culture or a certain sex.⁴⁶ Some patients do not want their tissue used (even without their names attached) for research on race and I.Q., race and crime, or gender and mathematical ability.⁴⁷ They fear that the findings of such research could label and stigmatize their group.⁴⁸

Norms that guide the disposition of body tissue reflect community ideals. Thus, in particular social contexts, the priorities for body use are not always the same as those advocated by scientists or commercial interests. Giving blood and body tissue rather than selling it, for example, is a way of encouraging altruism and affirming social connectedness by linking donors to strangers through donations in the interest of the public good. But these community ideals have clashed with commercial interests in the development of private cord blood banks and the patenting of the cord blood stem cell extraction technique. Those who believe that cord blood should be a public resource, freely available to those in need of therapy, have challenged companies that see patenting and privatization as essential for investment in research.⁴⁹

The wide range of social meanings placed upon the body—in defining community, reinforcing acceptable behavior and establishing priorities—have converged in disputes surrounding the Human Genome Diversity Project (the “HGDP”). Anthropologist Margaret Lock analyzes the objectives of the HGDP: to immortalize cell lines from indigenous peoples worldwide and, in particular, from the isolated populations who have unique genetic profiles due to their history of isolation and intermarriage.⁵⁰ Scientists claim that the cell lines of “genetically pure” populations are of special scientific interest as a means to reconstruct migratory history and disclose human genetic variation.⁵¹ But this plan to collect their cell lines has been politically and ethically controversial. Lock describes the major problems confronting the HGDP: the science itself (based on the notion of pure populations) is questionable; the claims that the

46. See Andrews & Nelkin, *supra* note 29, at 54 (portions of this article reproduced in this paragraph in their entirety with permission of the authors).

47. See *id.*

48. See *id.*

49. See George J. Annas, *Waste and Longing—The Legal Status of Placental-Blood Banking*, 340 NEW ENG. J. MED. 1521, 1521-24 (1999). See generally Jeremy Sugarman et al., *Ethical Issues in Umbilical Cord Blood Banking*, 278 JAMA 938 (1997).

50. Margaret Lock, *Genetic Diversity and the Politics of Difference*, 75 CHI.-KENT L. REV. 83, 83, 91-93 (1999).

51. *Id.* at 94-96.

research would benefit the community providing the DNA are often false; the reductionist approach ignores the social assumptions underlying the scientific claims and the ways in which scientific findings about human differences can be used for political agendas; and the project has made little effort to involve the individuals who are to provide the tissue samples for extracting their DNA.⁵² The increasingly commercial context of the research exacerbates these problems. In this context, Lock contrasts scientific claims with the responses of indigenous peoples who are concerned about the problems of regulating the research, the ownership of genetic material, and the potential for discrimination, stigmatization and eugenics on the basis of information about their particular genetic profiles.⁵³

Information from human tissue can be used for political purposes, such as denying an indigenous person's claims to land if his genetic profile does not match that of the appropriate ancestor group. But even well-intentioned medical uses of body tissue may have a larger political significance as historian M. Susan Lindee demonstrates in this volume. Lindee investigates a particular episode in the medical collection of human body tissue—the political history of the collection of babies' blood for PKU (phenylketonuria) testing.⁵⁴ She shows how the system of organization, manipulation and control of bodily materials, served prevailing political interests in constructing PKU as a compelling public health problem.⁵⁵ This disease, in effect, conformed to a network of political interests in the social management of genetic disease. The development of what appeared to be a diagnostic test that offered the prospect of intervention, quickly led to legislation mandating the test.⁵⁶ Even though many scientific questions remained, these mandates effectively closed off other options.

II. INTEGRATING CULTURAL MEANING INTO POLICY

Scientists seeking unimpeded access to human tissue argue that restraints on their ability to gain access to, manipulate and

52. *Id.* at 96-99, 100-101, 109-110.

53. *Id.* at 84-85.

54. M. Susan Lindee, *Babies' Blood: Fragmentation, Redemption and Phenylketonuria*, 75 CHI.-KENT L. REV. 113, 114-16 (1999).

55. *See id.* at 117-21.

56. *See id.* at 124-26.

commercialize tissue obstruct the progress of research and deprive society of useful medical benefits. But that argument is wearing thin with growing awareness of the downside of certain genetic advances. Genetic diagnosis of late-onset disorders have meant that many currently healthy people live under the Damocles' sword of knowing they are at enhanced risk for later illnesses such as breast cancer or Alzheimer's disease.⁵⁷ Current "treatments" such as prophylactic oophorectomy for women who learn they are at higher than average genetic risk for ovarian cancer may be risky, disruptive (causing the woman to lose her ability to have children), and unnecessary (since the majority of the women with the genetic mutation do not develop ovarian cancer).⁵⁸ Such "treatments" may also be ineffective because some women still develop cancer in the remaining tissue.⁵⁹

Moreover, claims about the benefits gained by unrestricted access to patient tissue have been exaggerated. A federally-appointed committee investigating gene therapy found that even though 567 Americans had undergone gene therapy in approximately one hundred different experiments, "there is still little or no evidence of therapeutic benefit [of gene therapy] in patients, or even in animal models."⁶⁰ The panel condemned most of the efforts as pure hype and expressed concern that in the rush to undertake gene therapy, the development of other easier-to-achieve conventional treatments for the same diseases was likely to be ignored.⁶¹ There appears to be a growing backlash against "genetic hucksterism."⁶²

Public attitudes also reflect concerns about the fragmentation of the body that is implied by genetic medicine. Molecular biologist Leroy Hood, for example, predicts a future in which "[y]our entire genome and medical history will be on a credit card Physicians will really then have to look at humans as complex systems analysis" and medicine will be "manned by mathematicians."⁶³ However,

57. See Ruth Hubbard & R.C. Lewontin, *Pitfalls of Genetic Testing*, 334 NEW ENG. J. MED. 1192, 1192-93 (1996).

58. See Andrew Berchuck et al., *Genetic Susceptibility Testing and Prophylactic Oophorectomy*, 82 EUR. J. OBSTETRIC & GYNECOLOGICAL REPROD. BIOLOGY 159, 160 (1999).

59. See *id.* at 162.

60. Laurie Garrett, *The Dots are Almost Connected Then What?: Mapping the Human Genetic Code*, L.A. TIMES MAG., Mar. 3, 1996, at 22.

61. *Report and Recommendations of the Panel to Assess the NIH Investment in Research on Gene Therapy* (Stuart H. Orkin & Arno G. Motulsky, co-chairs, Dec. 7, 1995) <<http://www.nih.gov/od/orda/panelrep.htm>>.

62. Keay Davidson, *DNA: High Hopes or Just Hype?*, HOUS. CHRON., Sept. 29, 1996, at 2.

63. Garrett, *supra* note 60, at 48-49.

delivering medicine in this way runs counter to people's growing interest in a more holistic view of medicine and increasing desires for treatments that view the patients as a whole rather than focussing on particular small parts.⁶⁴

Tensions between the potential contribution of unfettered research to scientific and medical progress and social concerns have been reflected in legal and policy decisions. A decade ago, in *Moore v. Regents of the University of California*,⁶⁵ a patient sued his physician and a biotechnology company alleging they had used his biopsied tissue without his consent and transformed it into a patented commercial cell line.⁶⁶ The court sided with the interests of the defendants. The court reasoned that giving the patient a property right to his tissue would impede progress and "destroy the economic incentive to conduct important medical research."⁶⁷

However, in more recent decisions, the federal government, professional societies, institutional review boards, and courts have considered values beyond economic incentives and scientific progress. Some institutional review boards, for example, have integrated cultural values into the protocols for the retrieval and use of human tissue, giving patients increased rights to control the uses made of their body material. Some physicians have claimed that they should not have to obtain Institutional Review Board approval and the informed consent of patients for undertaking genetics research because it only involved a "simple blood test." But the Office for Protection from Research Risks of the U.S. National Institutes of Health underscored why consent and external review are necessary: "Genetic studies that generate information about subjects' personal health risk can provoke anxiety and confusion, damage familial relationships, and compromise the subjects' insurability and employment opportunities."⁶⁸

When researchers sought to analyze previously-collected tissue samples at the Centers for Disease Control, an advisory group pointed out that "retaining tissue samples or immortalizing cell lines

64. See generally Lori B. Andrews, *The Shadow Health Care System: Regulation of Alternative Health Care Providers*, 32 HOUS. L. REV. 1273 (1996).

65. 793 P.2d 479 (Cal. 1990).

66. *Id.* at 480-82.

67. *Id.* at 495.

68. OPRR, PROTECTING HUMAN RESEARCH SUBJECTS: INSTITUTIONAL REVIEW BOARD GUIDEBOOK § 5, at 43 (1993).

may violate cultural or religious beliefs.”⁶⁹ Guidelines issued by the American College of Medical Genetics require that patients be asked for consent before research is done on their tissue samples and that patients have an option to have their samples withdrawn or destroyed at any time.⁷⁰

Even in the *Moore* case, the California Supreme Court held that the physician violated his fiduciary duty by not telling the patient in advance of surgery that he had a commercial interest in the tissue: “a physician who treats a patient in whom he also has a research interest has potentially conflicting loyalties.”⁷¹ The court expressed concern that “physician[s] . . . may be tempted to order a scientifically useful procedure or test that offers marginal, or no, benefits to the patient.”⁷²

And in a dispute between a couple and their physician over whether the couple could take their embryo to another facility for implantation, the court held that the embryo was the couple’s property even though housed in the physician’s lab.⁷³ The physician was merely the custodian of their tissue.⁷⁴

Courts have also recognized the psychological impact on families of how body parts of a deceased relative are treated. In one case, the U.S. Army—without notice to the family and without their consent—performed an autopsy on the body of a serviceman, removed certain body parts to be retained “indefinitely” and then cremated the rest of the body.⁷⁵ The court held that, even though the autopsy itself was not actionable, the parents could recover emotional distress damages for the removal of body parts and cremation.⁷⁶ The parents of the serviceman were entitled to \$210,000 in damages because the United States’ handling of the body violated the Jewish plaintiffs’ religious beliefs.⁷⁷

Cultural norms, too, are beginning to influence the treatment of body tissue. The North American Advisory Group to the Human

69. Clayton et al., *supra* note 4, at 1788.

70. See *American College of Medical Genetics Statement: Statement on Storage and Use of Genetic Materials*, 57 AM. J. HUM. GENETICS 1499, 1499-1500 (1995).

71. 793 P.2d at 484.

72. *Id.*

73. See *York v. Jones*, 717 F. Supp. 421, 425-27 (E.D. Va. 1989).

74. See *id.* at 427.

75. See *Kohn v. United States*, 591 F. Supp. 568, 570, 573 (E.D.N.Y. 1984), *aff’d*, 760 F.2d 253 (2d Cir. 1985).

76. See *id.* at 572-74.

77. See *id.* at 575.

Genome Diversity Project has stressed the importance of sensitivity to community values in the collection of tissue from indigenous groups.⁷⁸ They would require that the current process be handled in a culturally appropriate way—including the need for consent from a representative or the leader of the group or tribe, not just from the individuals being sampled.⁷⁹

This trend is part of a larger legal movement around the world that is giving increased respect to the emotional impact of violations of autonomy. As described by Kathy Laster and Pat O'Malley, courts throughout the world are beginning to reconsider the motivations, passions and particular circumstances of individuals.⁸⁰ Applied to the taking of human tissue, this trend recognizes the benefits that can accrue to individuals and society from respecting the cultural meanings of the body.

78. See Patricia Kahn, *Genetic Diversity Project Tries Again*, 266 *SCIENCE* 720, 720-22 (1994).

79. See *id.*

80. See Kathy Laster & Pat O'Malley, *Sensitive New-Age Laws: The Reassertion of Emotionality in Law*, 24 *INT'L J. SOC. L.* 21, 24-31 (1996).