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# The social life of genes: privacy, property and the new genetics

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## Abstract

With the advent of the Human Genome Project and widespread fears over human cloning and medical privacy, a number of states have moved to protect genetic privacy. Oregon's unique Genetic Privacy Act of 1995, which declared that an individual had property rights to their DNA, has provoked national and international interest and controversy. This paper critically reviews the literature on genetic privacy and gene patenting from law, philosophy, science and anthropology. The debate in Oregon, from 1995 to 2001, illustrates many of the key issues in this emerging area. Both sides of the debate invoke the property metaphor, reinforcing deterministic assumptions and avoiding more fundamental questions about the integrity of the body and self-identity. The anthropological critique of the commodification of the body, and the concept of 'embodiment' are useful in analyzing the debate over DNA as property. © 2002 Elsevier Science Ltd. All rights reserved.

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What is at stake is whether those genes that make up human beings are the 'shared heritage of humanity' or whether, for the sake of research and progress in medicine, they can somehow have property rights, monopoly rights, or commercial development rights attached to them. What is also at stake, for that matter, is determining whether this is a fallacious dilemma, insofar as medical progress could occur through other funding schemes, which might be more favorable to health policies designed for the common good.

UNESCO, "Intellectual Property In the Field of the Human Genome"

## Introduction

In an earlier version of this paper, I began with the question, "Do you own your DNA?" Yet, the more I consider the complexities of gene patenting and genetic privacy, the more I think the question to start with must

be, How did genes become commodities? Scientific and legal changes are of course central to this development. Condit identifies the transformation of the biosciences into biotechnology in the 1980s as critical to the commodification of genes (Condit, 1999, p. 159). Others cite changes in US patent laws and the development of recombinant DNA technology (Andrews & Nelkins, 2001, p. 43). Rifkin (1998) points to the US Supreme Court case of *Diamond v Chakrabarty* in 1971 as an especially important turning point. Equally important, however, is the social process by which the body and its parts, even its most microscopic parts, have come to be thought of as a source of wealth. With the discovery of the structure of DNA in 1953 and the initiation of the Human Genome Project (HGP) in 1986, the gene has become a cultural icon *and* a valuable commodity. Despite the growing commercialization of genes, it is equally clear that there is significant cultural resistance to such commodification. Public opinion polls suggest widespread suspicion about the use of human subjects for DNA research along with deep concerns about ethics and privacy. Social critics worry that commercial interests negate or ignore the social meanings of the body.

Exclusive licenses to DNA sequences through patent protection could bring biotech companies billions of

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dollars in the development of new drugs, gene-based therapies, and diagnostic tests. Others have sought to confer property rights on individuals to their DNA, thus protecting them from potential employment and insurance discrimination and unwanted participation in research. We need to ask what gets left out when property dominates the debate over DNA? This essay considers the debate over genetic privacy and property in the context of the commodification of the body and its parts. The controversy surrounding Oregon's Genetic Privacy Act (Senate Bill 276/95, see Oregon Statute 659.700) offers a useful case for exploring the application of property metaphors to human DNA.

### Do genes have social lives?

The contributors to the edited volume *The Social Life of Things* (Appadurai, 1986) begin with the intriguing premise that commodities have social lives. As Igor Kopytoff explains, for example, "From a cultural perspective, the production of commodities is also a cultural and cognitive process: commodities must be not only produced materially as things, but also culturally marked as being certain kinds of things" (1986, p. 64). Things may be marked for exchange in one social or historical context and not another. A thing might be said to have a biography, or life history, moving in and out of the commodity state (Appadurai, 1986, p. 18). Moreover, there is in any exchange system a tension between "the tendency of all economies to expand the jurisdiction of commoditization and of all cultures to restrict it" (Appadurai, 1986, p. 17; see also Kopytoff, 1986, pp. 72–73). In the West, people have proven particularly resistant to commodification.<sup>1</sup> Kopytoff suggests, however, that the human sphere may become increasingly vulnerable to commodification "especially in a secularized society that finds it increasingly difficult to appeal to any transcendental sanctions for cultural discrimination and classification" (1986, p. 84). These insights on the nature of commodities and commodification are particularly useful as a starting point for discussing how human genes have become commodities, and how their commodification has been resisted.

Demand, Appadurai explains, is not only a mechanical response to supply, but rather is "a complex social mechanism" (1986, p. 41). Demand for genetic research may seem self-evident—the promise of longer life, better health care, higher quality of life; but just as we learn to think of ourselves as a product of our DNA, we learn (through media representations and scientific discourses)

that we need genetic medicine. The desire for full hair, thin bodies, even longevity, is socially constructed: we are taught to want these things, just as we are taught that the secret is in our genes (Consider the recent book title that implores one to *Turn off the Fat Genes*).

### Yours, mine and ours: contested DNA

Why has the New Genetics stirred such concerns over privacy? Several characteristics of genetic information make it unique from other kinds of medical records. First, genetic tests can be predictive of future health. DNA testing can be used, for example, to identify carriers of the mutations that are believed to cause breast cancer and Huntington's disease. It is even possible to learn about someone's likely future that even the individual does not know, which led some observers to consider our DNA a "coded probabilistic future diary" (Annas, 1996, p. 20). Another term used to describe DNA is that of the genetic "blueprint", a metaphor that points to the deterministic assumptions embedded in contemporary understandings of genetics. As James Watson, former director of the HGP, once declared, "We used to think our fate is in the stars. Now we know, in large measure, our fate is in our genes" (quoted in Weiner, 1994, p. 31). Many observers worry that such determinism tends to ignore the social, economic and environmental factors involved in disease, as well as the value judgements inherent in definitions of "normal" and "abnormal" (see Lloyd, 1994). Genetic information is also unique because it implicates families and groups. As the authors of the GPA explain, "Decoding DNA also divulges information about a person's parents, siblings, and children, and can therefore affect how family members perceive and relate to one another" (Annas, Glantz, & Roche, 1995, p. 3).

Given these unique characteristics, genetic information is potentially valuable to employers and insurance companies, and to researchers and pharmaceutical concerns. The growing demands for privacy and the protection of genetic information, then, emerges directly from this growing commercialization.

A number of commentators argue that in light of the accessibility of medical records generally, especially with increasing computerization of records and the growth of the internet, genetic information will require special (Annas, 1993; Lebacqz, 1994).<sup>2</sup> According to George Annas, a leading voice in the genetic privacy movement, "Genetic information is both potentially embarrassing and uniquely personal. The existence of such decodable information could either impel us to take privacy much

<sup>1</sup>Kopytoff acknowledges that slavery clearly belied the conceptual separation between "the universe of people and the universe of objects" but noted that slavery was a moral problem in the west and not elsewhere (1986, p. 84).

<sup>2</sup>For background on legislation regarding medical records and the handling of genetic information specifically, see Congressional Digest (2000a, b).

more seriously in the genetic realm than we have in the medical and criminal realms, or lead us to give up on maintaining personal privacy altogether” (Annas, 1993, p. 106). A few recent surveys suggest that the public does have strong concerns about their privacy and the effects of genetic research. A CNN-Time Magazine poll in June 2000, for example, found that 46 percent of respondents thought that obtaining the genetic code would have harmful consequences (LA Times, 28 June 2000). A Gallup survey in September 2000 asked Americans about their concerns over medical privacy. An overwhelming majority (93 percent) responded that medical and government researchers should not be allowed to study an individual’s genetic information unless they first obtain his or her consent (Institute for Health Freedom, 2000).

Efforts to pass genetic privacy legislation often focus on the threat of employment and insurance discrimination. While evidence of actual discrimination has been largely anecdotal, the media have reported on a number of cases of interest. In one recent case, the federal government sued Burlington Northern Santa Fe Railroad for requiring genetic testing of employees filing claims for work-related injuries. The company asserted that some workers were genetically predisposed to carpal tunnel syndrome, thus making them ineligible for work-related claims (*Oregonian*, 10 February 2001, p. 10a). The best known example of widespread abuse is the employment and insurance discrimination that resulted from sickle-cell anemia screening programs in the 1970s (see Murray, 2001). The Air Force Academy also used the results of such screenings to exclude carriers (see Hubbard & Wald, 1999, p. 34). More recent accounts cite the use of genetic information to deny medical benefits to retirees (Fuller et al., 1999, p. 1359). In the United Kingdom, the government has recently allowed insurers to refuse coverage or increase premiums based on predictive genetic tests (BBC News Online, 12 October 2000). A recent survey of 1500 genetic counselors and physicians reported 785 cases where patients had lost jobs or insurance because of a genetic condition or test.<sup>3</sup> A survey by the American Management Association found that 30 percent of large and mid-size companies sought some form of genetic information about employees and 7 percent used that information in hiring and promotion decisions (Martindale, 2001, pp. 19–20). Citing other examples of genetic discrimination, Andrews and Nelkins conclude, “the body in the biotechnology age betrays” (2001, p. 98). In order to prevent such discrimination, 33 states have enacted legislation dealing with health insurance discrimination based on genetic testing, and 19 states have

laws regarding employment discrimination and genetic testing (National Cancer Institute, 1999, see also National Conference of State Legislatures, 1999).

Privacy, particularly in relation to genetic testing, does not only imply the right to keep others from accessing and using one’s genetic information. “Genetic privacy” advocates also include the right not to share information with others, but also the right not to know one’s own genetic fate, as well as the right to use information in accordance with one’s own values (see Lebacqz, 1994, p. 40). Observers worry, for example, about the psychological effects of learning one’s predisposition to a deadly disease, particularly in the absence of any effective treatments (Johnson, Wilkinson, & Susan Taylor-Brown, 1999). Not only could this lead to detrimental psychological effects for individuals and their families, but it could also lead to a kind of stigmatization and societal discrimination that goes well beyond the economic concerns of most legislation to date. As Annas puts it, “Genetic information can be toxic” (1996, p. 19).

Some argue that the prospect of labeling healthy people as patients may discourage many from genetic testing, or at the very least encourage people to protect their genetic information (see Martindale, 2001, p. 20). Medical information, particularly genetic information, would seem to have the power to both liberate and constrain individual choice. Nowhere is this more apparent than in the alarmist references to the ‘new eugenics’. One observer calls worries of a ‘new eugenics’, in other words the idea that genetic “defects” can and should be eliminated from the population, “the approved [Human Genome] project anxiety” (Paul, 1994, p. 143). Media reports are full of warnings about the dangers of coercive policies that would seek to weed out genetic mutations. The solution, according to many, is individual choice and autonomy in genetic counseling and screening programs. Still, a number of ethicists argue that privacy and individual choice are problematic. Even in the absence of coercive policies, they argue, there will be social pressures to screen for certain disorders, and pressure to use information in certain ways. Rifkin (1998) foresees a “eugenic civilization” in which we will be able to reengineer our species to suit our own whims and desires. Ridley, on the other hand, argues that the key distinction between current genetic technologies and the eugenics movement is coercion: “genetic screening is about giving private individuals private choices on private criteria. Eugenics was about nationalizing that decision to make people breed not for themselves but for the state” (Ridley, 1999, p. 299). Rapp predicts that contemporary eugenics dilemmas will have more to do with the market economy rather than coercive policies: “Threats of eugenic exclusions now involve insurance coverage or its lack, employer discrimination, and struggles around

<sup>3</sup> Another study of genetics counselors argued that while fears of discrimination are high, the actual risk of insurance or employment discrimination were quite low (Hall & Rich, 2000).

extending coverage of disability legislation to those with genetic susceptibilities” (2000, p. 37).

Others worry that the New Genetics may help turn social problems into personal problems, placing blame and responsibility for social ills on individuals. Moreover, the more genetics becomes a legitimate tool for explanation of normal and abnormal, disease and health, the more we may turn away from other forms of explanation—social, physical and environmental (see Finkler, 2000, p. 49).<sup>4</sup> This could be particularly detrimental to women, the poor, and minorities. As Lebacqz argues, for example, “Privacy does not change [the discourse of discrimination] but only reinforces it: social problems become privatized and turned back onto oppressed people” (Lebacqz, 1994, p. 48).<sup>5</sup>

### The commerce of genes

Like demands for privacy, informed consent has become a major issue in genetic research precisely because of the growing potential for commercialization. Researchers may want to avoid obtaining informed consent for the use of human tissues, worrying that the process will slow down or threaten potentially lucrative discoveries. At the same time, the perception that genes are a source of wealth fuels public suspicions about the ethics of DNA research. We might ask not only who owns our genes, but also to what extent we are able to give or withhold consent to researchers who want to use our DNA.

Gene patenting is of course at the center of this debate and intimately tied to privacy concerns. The efforts of Decode Genetics, an Icelandic subsidiary of a US company, to identify the genetic causes of diseases such as cancer by using the medical records, genealogies, and genetic information of the entire country, has brought

<sup>4</sup>The mapping of the human genome, as Rothman explains, requires choices about what constitutes “normal”: “Certain political and ethical issues make themselves immediately apparent: which do you think will be the standard, the allele that is believed to ‘cause’ homosexuality, or that which is believed to ‘cause’ heterosexuality” (Rothman, 1999, p. 96).

<sup>5</sup>The debate over prenatal screening is beyond the scope of this paper, but see Parsons (1997, p. 253) who similarly argues that screening programs have the risk of placing blame and responsibility on individual parents and poses a narrowly medical solution to disability rather than challenging societal assumptions about normal/abnormal.

On the effect of the HGP on minorities, see also the Zilinskas and Balint (2001) volume, which emphasizes the possible benefits of the HGP for minority communities, who are at higher risk for many health problems. Murray (same volume) argues that past abuses, such as the sickle-cell screening program, can be avoided with privacy protections.

the issues of informed consent, privacy, and property together. In Iceland, an individual is assumed to have consented to have their DNA and medical records used for research unless they opt out by notifying his or her physician. Annas (2000) is critical of this “presumed consent” and argues that individual consent should be required. He also questions whether real benefits will be delivered to the Icelandic people that outweigh the risks. Any research that could result in stigmatization or discrimination of the Icelandic people should require the consultation of the population, he argues. Informed consent requires an adequate assessment of risks and benefits—psychological, physical, and social (see Johnson et al., 1999). The project certainly begs the question, how does an entire country give informed consent? Despite assurances that records will be encrypted and individual identities protected, critics worry about loss of privacy and potential discrimination. While proponents say it will be good for the Icelandic economy, others say it is unfair for one company to benefit from such a potentially valuable resource.

In the United States, researchers frequently request waivers of informed consent requirements, not only when samples are used anonymously, but when samples are linked to clinical information through encryption. Researchers argue that these projects pose little or no risk to the people from whom samples were originally taken. But promises of confidentiality may not always be realistic, even in studies involving large populations such as Iceland. For example, it would be difficult if not impossible to guarantee the confidentiality of persons with rare disorders (Clayton, 1998, p. 129).

The Icelandic case exemplifies the battle over the commercial use of human tissue, and of genetic information in particular. Biotech companies have flooded the federal patent office with applications to patent newly discovered genes. The standard for patentability is that an invention must be new, useful and nonobvious, yet genes are naturally occurring substances. This contradiction has caused outrage, even within the medical community. The American College of Medical Genetics, for example, has taken the position that genes should not be patented, and cites the growing evidence that patents limit access to genetic screening, negatively impacting patient care. Organizations representing those affected by genetic conditions have taken a similar position (Visco, 2000; Meyers, 2000; Nader, 2000). While the US Patent and Trade Office issued stricter guidelines for patents on genes in 2000, these organizations remain opposed to gene patenting under any conditions.

Companies are also trying to own patents to random DNA sequences, even without knowing their function or where they occur on chromosomes (Hubbard & Wald,

1999, pp. 124–5).<sup>6</sup> The patenting of such random sequences has been particularly controversial. As one bioethicist told the USA Today, “It’s like patenting the alphabet and charging people every time they speak” (USA Today Online, 25 September 2000). Others argue that unfettered gene patenting reflects the market-driven approach to research that can have negative effects on the advancement of science, and ultimately on patient care (Knoppers, Hirtie, & Glass, 1999). While the biotech industry argues that it is the profit motive that drives new research, that competition may also hinder collaboration when information is not shared freely by researchers around the world. Heller and Eisenberg (1998, p. 698) describe an emerging scenario they call the “tragedy of the anticommons” in which “too many owners hold rights in previous discoveries that constitute obstacles to future research”. Bill Clinton and Tony Blair expressed those concerns in March 2000, when they issued a joint statement urging scientists to release the raw data from the HGP. The statement came days after negotiations to merge the public and private efforts to map the genome broke down. When the US and Britain agreed to share data from the publicly funded project, the Nasdaq stock exchange fell on the news. Biotech companies that had been banking on selling genetic data to pharmaceuticals and researchers fell sharply, indicating that the open exchange of information is not good for business (LA Times, 14 March 2000).

While some analysts argue that DNA should be the property of individuals, and others argue that those who ‘discover’ genes should earn the right to patent them, case law on whether or not human tissue can be considered property at all is contradictory. According to Markett, “The common law has a long tradition of denying persons property rights in their bodies” (1996, p. 216). With the exception of blood and semen, humans do not have commercial rights in their body parts. Markett argues that because body parts have increased in value, the courts should recognize commercial rights. The often cited California Supreme Court case of *Moore v. Regents of the University of California* illustrates the difficulty in recognizing property rights to donors of human tissue.

When John Moore sought treatment at the UCLA Medical Center for hairy-cell leukemia, he was apparently unaware that his removed spleen and other samples were being retained by his doctor for research purposes. When Moore eventually learned that his tissue enabled the creation of a cell-line potentially worth billions of dollars, he sued his doctor and the University

of California, arguing that his samples had effectively been stolen from him, and claiming a share of the profits. The court, fearing a chilling effect on research, found that Moore had forfeited any rights he had to his tissue because he did not retain possession or assert ownership of his spleen once it had been removed. Proponents of gene patenting often refer to the Moore case as a clear precedent denying donors a share in the profits from discoveries made using their tissues. Other cases, however, do seem to recognize DNA as property.<sup>7</sup> Critics of the Moore decision argue that without recognizing a donor’s property interest in their tissue, most states offer little legal recourse to those who feel their DNA has been used without their consent (Markett, 1996). Rao offers a different critique of the Moore decision. She finds the court’s ruling contradictory in that it rejected Moore’s property claim to his spleen while upholding the researchers’ property rights to the resulting cell lines. “The case does not stand for the proposition that spleens can never become property...it simply holds that Moore’s spleen was not his property” (Rao, 2000, p. 374). Some even argue that the rising value of human tissue merits the creation of a royalty system, much like that used in the music industry, that would compensate donors for each use of their tissue (Lin, 1996, p. 121).

Another battle over the commercialization of a specific gene highlights the conflicting interests of researchers and their subjects. When several families affected by Canavan’s disease, a fatal and rare recessive disorder, allowed their children’s tissue samples to be used for research, they hoped that a prenatal diagnostic test for the disorder and new treatments would be developed. Many of the same families were outraged when Miami Children’s Hospital, where researchers identified the mutation which causes the disorder, patented the gene and began charging a royalty fee on each test for the disorder. In some cases, the very families that had helped make the research possible were later being charged a fee when testing for the disorder in other family members. The hospital argued that the royalty would help them recover some of the millions of dollars they put into finding the gene. They also reasoned that a laboratory with an exclusive license would be more likely to market the test to at-risk families (see Miami Herald, 15 December 1999, p. 8b; see also Andrews & Nelkins, 2001, pp. 51–52). In a letter

<sup>6</sup> Louisiana has defined genetic information as the property of the individual. Like Oregon, the law exempts anonymous research and makes other exceptions. Louisiana Administrative Code, June 1999, Chapter 45, Regulation 63, p. 255.

<sup>7</sup> Markett and others cite *United States v. Arora*, *York v. Jones*, and *Davis v. Davis* as recognizing a property right in human tissue. The latter established a property interest in frozen sperm. According to Markett, these cases establish that “A court must recognize property rights in a donor’s body parts where, through enforcement of a contract or through a tort action, the donor seeks return of, or damages for, misuse of his or her body parts” (1996, p. 225).

to the editor of the Miami Herald, one parent of a child who died of Canavan disease explained that the hospital had failed in its obligation to obtain informed consent from the families:

While we did give samples voluntarily to help eliminate a disease that was killing our children, we did not give consent to the research in writing as required by federal law, and we were not informed that our mutations would be patented. We also were not informed that Miami Children's would charge a royalty to any laboratory testing for one of our Canavan-disease mutations and then limit the facilities that can perform the test. Miami Children's Hospital claim that its profit-driven approach to licensing will encourage at-risk families to be tested is self-serving fantasy. (Miami Herald, 2 December 1999, p. 8b).

The controversy over the patenting of this particular mutation is especially significant, because it indicates that while the subjects of DNA research are quite often not interested in getting a share of the profits, they are concerned about retaining some control over the use of their DNA through informed consent procedures.

In fact, what this and other similar conflicts between researchers and subjects may show is that what many research subjects want is not privacy, not even profits, but assurances that their body parts will not be turned into marketable products. At present, informed consent is required for federally funded research through the Common Rule and with oversight by Institutional Review Boards.<sup>8</sup> While much of the focus of legislation to date has been on protecting privacy, researchers continue to be able to use DNA that is "anonymous" or linked to a subject through encryption without informed consent. Whether their privacy is violated or not, however, many people are uncomfortable with the idea of the commercialization of their DNA or tissue.

### Commodified bodies, commodified DNA

The commodification of the body is not a new phenomenon; slavery, prostitution, and the sale of corpses, for example, attest to this fact. However, new biotechnologies do challenge and expand the ways in which we value the body. As Gold explains, "The products of biotechnology from gene therapies, to hormones, to pharmaceuticals are things that we buy and sell, and trade. The body itself, when understood as the mine from which we extract these products, is similarly valuable as a commodity" (Gold, 1996, p. 2).

The commodification of the body is closely associated with "medicalization" the dehumanizing process by which "even living bodies are quickly fragmented and transformed into scientific work objects" (Sharp, 2000, p. 298). Objectification is necessary for transforming persons and their bodies into objects of economic desire. Some even argue that new biotechnologies, especially genetic engineering and cloning, encourage "self-objectification", in which we may see ourselves as both "subject and object, transformable and literally creatable through biological engineering" (Morgan, 1999, p. 30, cited in Sharp, 2000, p. 297).<sup>9</sup> The recent disclosure of genetically altered babies born in the UK suggests that this objectification is already evident (Whitehouse, 2001). Andrews and Nelkin point to the increasingly commercial language of science as a reflection of this objectification: "Body parts are *extracted* like a mineral, *harvested* like a crop, or *mined* like a resource" (2001, p. 5, emphasis in original). Not surprisingly, the metaphors of scientific language conflict increasingly with the social meanings of the body.

Anthropologists, in particular, have criticized this separation of body and self that allows for the commodification of the body and its parts. "Embodiment" refers to the notion of the body-as-self and to the rejection of the separation of body and self in medical practice (see Sharp, 2000, p. 290). One of the most fruitful areas of medical anthropology has been the reconceptualization of the body and the rejection of the Cartesian separation of mind and body. Medical anthropologists blame Descartes for the "mechanistic-materialistic background to biomedicine" (Strathern, 1996, p. 5). A refinement of the "mindful body" concept advanced by Lock and Scheper-Hughes (1987), embodiment "collapses the duality of mind and body...essentially by infusing body with mind" (Strathern, 1996, p. 181).

De Witte and Ten Have, in examining body commodification in the context of genetic material, argue "The distinction between person and body is contrary to the existential identity with our bodies and the self-experience of ourselves as embodied selves" (De Witte and Ten Have, 1997, p. 52). Despite such reservations, court decisions tend to favor valuing the body, like other "goods", in economic ways. The famous Moore decision, discussed above, exemplifies this tendency: the court rejected Moore's attempt to claim his spleen as his property, but did not challenge the doctor's patent claim on Moore's cell line. Gold, a critic of the Moore decision, argues more generally that "courts allocate right of control to those individuals who present themselves to the court as valuing the contested good in terms of economic modes of valuation" (1996, p. 17).

<sup>8</sup>See Office of Science and Technology Policy (1991) for the "Common Rule".

<sup>9</sup>For example, see the recent revelation about genetically altered babies in the UK (BBC News Online, 4 May, 2001).

A similar pattern has emerged in public policy and legal decisions around the ownership of DNA. While the United States has one of the most liberal policies regarding the patenting of DNA sequences, courts, as well as state and federal legislators, have largely rejected the notion that an individual could claim ownership of his/her DNA either for the purposes of protecting their privacy or for claiming a share of profits derived from their genome.<sup>10</sup>

Not surprisingly, there has been considerable resistance to the commodification of the body, and gene patenting is no exception. Before turning to the objections to gene patenting, however, it might be useful to look at the debate over organ donation, which offers certain similarities. Due to a perceived shortage of organs for transplant, some suggest a market approach, in which individuals would be allowed to sell their own organs. Andrews, for example, argues that individuals should have the right to sell their organs, while claiming that this would not contribute to the commodification of the body: “I am not advocating that people be treated as property, but only that they have the autonomy to treat their own parts as property, particularly their regenerative parts” (Andrews, 1992, p. 2151). As with the debate over genetic ownership, as will be discussed below, it seems difficult to believe that one could have it both ways. Childress rejects the sale of organs, primarily because he does not believe it would increase supply and might have the opposite effect (Childress, 1992, p. 2145).

According to Joralemon, the controversy over procurement strategies “signal[s] an ongoing cultural dispute over the meaning of the body as its parts acquire utility beyond their natural anatomical function” (Joralemon, 1995, p. 336). Joralemon argues that there is considerable cultural resistance to transplantation as it promotes the notion of the body as a collection of replaceable parts rather than integral to the self. An example of such resistance occurred in Brazil with the passage in 1997 of a “presumed consent” law for organ donation. The law made every citizen a potential organ donor, unless an individual went to the considerable trouble of having himself or herself declared a “non-donor”, something particularly difficult for poor and illiterate individuals to accomplish. In a country where urban legends about organ stealing for profit abound, the Presumed Organ Donor Law prompted widespread fear and anger (McDaniels, 1998). The law was repealed only one year later with pressure from the medical community.

This debate relates very well to the drive to commodify genes and the cultural resistance to that commodification. In terms of the implications of new biotechnologies for the conceptualization of the body,

the focus on property and autonomy is problematic (see Sharp, 2000, p. 299). Most do not question whether or not DNA can be claimed as property, but rather by whom—the researchers who discover “new” sequences and mutations, or the individuals from whom such discoveries are mined. By countering biotech efforts to patent the genome with assertions of individual ownership rights to the body and to one’s DNA, opponents of patenting fail to address the fundamental issue of body fragmentation and commodification. By rejecting individual property claims to DNA, patenting advocates contradict themselves when defending the notion of DNA as an invention of the laboratory. This contradiction will be illustrated with the Oregon example below.

According to Sharp, the era of the New Genetics makes possible “bodily fragmentation par excellence” as well as the notion that the essence of our humanity is located in our DNA (2000, p. 309). Such genetic determinism, according to Rabinow, represents the ultimate displacement of the soul in Western discourse (Rabinow, 1992, cited in Sharp, 2000, p. 309). Some have argued that the denial of individual property rights to the body constitutes a loss of our identities to the biotechnology industry, an argument I myself made (see Everett, 1999). However, it may be more accurate to say that we lost our identities when they became reduced to our DNA. Finkler (2000) aptly describes this determinism as the “hegemony of the gene” and illustrates the disquieting ways in which the new genetics affects family relationships, our identities and our bodies.<sup>11</sup> According to Finkler, the new genetics promotes the “medicalization of kinship”, whereby family and kin are increasingly conceived in biomedical terms. No wonder so many are fighting to own their DNA, having been encouraged by the media and scientists alike to believe they *are* their DNA. As one proponent of individual property rights to DNA argued, “DNA is you, it’s the coding for the most important part of you—your own body...The ability to own yourself is a basic right” (Onion, 2001, p. 2).

### Genetic privacy: the debate in Oregon

Critics of the Moore v. Regents decision argue that passage of the GPA would resolve the legal uncertainty over commercial rights in human tissue, thus adequately protecting individuals (Lin, 1996; Markett, 1996). Others argue that giving individuals the power to prevent research on their tissue in an anonymous form is socially harmful, and that the provisions of the GPA related to informed consent would be too costly to

<sup>10</sup> For a comparison of patent policies in different countries, see UNESCO, (2001).

<sup>11</sup> See Lippman (1993) and Hubbard and Wald (1999) for similar discussions of “geneticization”.

enforce (Reilly, 1995, pp. 379–380). Another critic reasoned that because DNA is only a “blueprint”, and cannot predict with certainty a person’s medical future, additional protections were not necessary; genetic information could be protected like other medical information (Troy, 1997). Others have even argued that special protection for genetic information will do more social harm than good by reinforcing genetic determinism (Wilcox et al., 1999).

The issues outlined above prompted a number of leading bioethicists to craft the Genetic Privacy Act in 1995 (Annas et al., 1995). The proposal for national legislation intended to protect privacy and guarantee informed consent for subjects of DNA testing. The act’s provisions included the requirement of informed consent for the collection, analysis, and disclosure of DNA information, a statement that DNA is the property of the individual, and a requirement that DNA samples must be destroyed when analysis has been completed. To date, the federal government has failed to enact comprehensive legislation governing genetic privacy.<sup>12</sup> In the absence of such federal legislation, many states have acted to protect privacy and discourage discrimination, including Oregon, which in 1995 became the first state to declare DNA to be the property of the individual. Since 1995, academic researchers and the pharmaceutical lobby have challenged the law, arguing that it inhibits important research and damages the biotech industry in the state by clouding intellectual property rights. In 1999, an effort to eliminate Oregon’s property clause ended with the creation of a government committee charged with reporting to the legislature on how best to protect genetic privacy. After the death of my son from a rare genetic disorder, I wrote in the newspaper about my own concerns over genetic privacy and the treatment of research subjects, and was asked to serve on the committee as a “consumer” representative.

Though the GPA has sparked much debate and discussion nationally, Oregon and Louisiana are the only states to enact its property provision. Efforts to

pass similar legislation failed in Maryland, where a bill modeled on the GPA was opposed by the medical society, insurance industry, and chamber of commerce, the latter arguing that it would discourage the development of a biotech industry in the state (Holtzman, 1995). After the New Jersey legislature passed genetic privacy legislation, Governor Christie Todd Whitman replaced the property clause with privacy protections, citing the potentially negative effect the former would have on research (Stepanuk, 1998). Michigan similarly rejected the property approach with more cautious privacy protections (Calvo, 2000). Public and private leaders of the HGP, as well as biotechnology spokesmen, typically support these measures. By reassuring a nervous public about privacy, while excluding individuals from making property claims, they create a predictable environment in which to do business. As of January 1999, 44 states had enacted legislation of varying scope concerning genetic privacy or discrimination (Mulholland & Jaeger, 1999).<sup>13</sup>

The Oregon Genetic Privacy Act of 1995 (SB 276/95) was the state’s first attempt to regulate the collection, retention and disclosure of genetic information. Previously, genetic privacy concerns had been only partially covered by civil rights law and specific mandates about research. A group of geneticists, lawyers and bioethicists concerned about genetic privacy formed the Oregon Genetic Privacy Advisory Committee (OGPAC) in 1994 and proposed the law. Their primary concern was to prevent insurance and employment discrimination based on the results of genetic tests. The law identifies the circumstances under which genetic tests may be conducted, and when insurance companies can use an individual’s genetic information. The most controversial aspect of the bill by far is the “property clause”, which simply states that “An individual’s genetic information is the property of the individual” (SB 276, Section 4). During the 1997 legislative session, the statute was subsequently revised to exempt samples used for anonymous and encoded research, another point of controversy (ORS 659.715, par. 1). OGPAC believed that the property clause would give courts clear guidance on the nature of an individual’s rights in genetic information. In other words, a person whose genetic information had been retained or disclosed without informed consent could effectively argue that their DNA had been stolen and pursue damages.

<sup>12</sup>A few federal laws may provide limited protections for genetic privacy. The Health Insurance Portability and Accountability Act of 1996 (HIPPA) prevents insurance companies from treating a predictive genetic test as a pre-existing condition. The Americans with Disability Act (ADA), while not mentioning genetic conditions specifically, may provide some limited protections against discrimination. See Jones, 1996. Weiner (1994) documents the history of congressional failure to prevent or control the negative effects of biomedical research. In June 2000, the US Senate voted on a fairly weak bill addressing insurance discrimination, but the House has yet to take it up. House Republicans have stalled a bill sponsored by Democrat Louise Slaughter, some saying that there is no evidence of genetic discrimination to date and therefore no urgency to the legislation (LA Times, 28 June 2000). See also Draper, 1999.

<sup>13</sup>It is important to note that there is little evidence to date to support the notion that the public finds such laws reassuring. For example, a recent study of genetics counselors found that while privacy concerns were widespread among those who sought genetic counseling, testing decisions were based more on the urgency of the information sought or the psychological effects of testing on individuals and families rather than on privacy concerns (Hall & Rich, 2000).



OGPAC reasoned that this was an easy concept for laypersons and the courts alike to understand. They also argued that the clause would allow blood relatives to assert ownership of genetic information that could be damaging to their own privacy through existing inheritance laws (GRAC minutes, December 1, 1999).

Changes to the Oregon GPA in 1997 and 1999 provided protections for anonymous and encoded research, exempting such testing from the informed consent requirements. Also during the 1999 session, the Pharmaceuticals Researchers and Manufacturers of America (PhRMA) and Oregon Health Sciences University (OHSU), where most biotech research in the state is done, led an effort to eliminate the property clause, replacing it with a vague mandate to protect patient privacy and confidentiality. The Oregon Senate approved the bill, but the House rejected it, and instead appointed a committee to study the question and make recommendations for the 2001 session (SB 937/99). Composed of representatives from government, industry, the medical profession, and health care consumers, the Genetic Research Advisory Committee (GRAC) met from October 1999 to November 2000.

As a member of the committee, my own thoughts on genetic privacy were admittedly guided as much by emotions as by theory. My son, Jack, died in 1998 as a result of a rare genetic disorder, the mutation for which had not yet been discovered. While the disorder affects no more than a few hundred individuals in the world, researchers believe it may reveal valuable information about the genetic basis of more widespread diseases, particularly skin cancers. My husband and I agonized over the decision to allow researchers to use Jack's tissue samples after his death. In an opinion column in the newspaper, I wrote, "Is it appropriate to consider DNA 'private property?' I cannot answer that in the abstract, but I do know that I feel very 'proprietary' about my son's cells" (Everett, 1999). I joined the GRAC probably with the notion that I was there to defend the property clause, which I felt underscored individual and family rights to retain control over the use of one's own DNA. By the time the GRAC completed its work, however, I was less certain of the benefits of declaring DNA to be the property of individuals. I was troubled by some suggestions that individuals should share the profits of discoveries made using their DNA, or even that individuals might be allowed to accept payment in exchange for consent to use their DNA. How could such benefits be distributed when family members share even rare mutations? How could informed consent be protected with the coercive effects of payments? I began to feel that the proponents of individual property rights were encouraging, perhaps unwittingly, the very commodification and objectification that I had found so troubling in my own experience. In the end, I lent my support to the elimination of the property clause.

The voices against the property clause typically focused on the threat it posed to the development of a biotech industry in Oregon. In criticizing the property clause, James Gardner, lobbyist for PhRMA, told the Oregon Senate that "The business climate in Oregon is inhospitable to the fledgling Oregon biotech industry" (Gardner, 1999, p. 1). By considering DNA the property of the individual, a company's intellectual property rights to research discoveries would be clouded. He further argued that the property clause could create a situation in which an individual could sell his or her DNA, effectively selling one's privacy rights. Gardner repeated these concerns to the GRAC, where he represented PhRMA (December 1, 1999 minutes) and in media interviews (see Onion, 2001). Other lobbyists warned the committee that Oregon was losing out on biotech dollars because of its unique statute. A representative of Smith Kline Beecham told the committee that her employer had decided not to fund research in Oregon until the property issue was resolved (GRAC minutes, 1 December 1999). Lawyer William Noonan argued that the property clause conflicted with federal patenting laws, and also warned that risk-averse corporations would do business in other states rather than fund research and development in Oregon (GRAC minutes, 5 January 2000). Representatives of OHSU claimed that the medical school had been unable to participate in certain national studies because of the Oregon law.

Several members of the committee challenged the assertion that the growth of the biotech industry had been hampered by Oregon's unique statute (GRAC minutes, 3 May 2000). Representatives from OGPAC further argued that deleting the property clause would seriously compromise the protection of privacy rights. In his testimony to the Oregon Senate in 1999, Bradley Popovich, chair of OGPAC, argued for an alternative that would keep the property clause while allowing tissue banks to use archived specimens under the regulations of the federal "Common Rule" (Popovich, 1999).

While property was the most controversial issue, the committee also considered other matters related to genetic privacy, such as issues of informed consent. OGPAC representatives, following the lead of the National Bioethics Advisory Commission (NBAC, 1999), expressed concerns about the use of clinical specimens for research (GRAC minutes, June 7, 2000). With regard to informed consent, the NBAC report recommends that "when informed consent to the research use of human biological materials is required, it should be obtained separately from informed consent to clinical procedures" (1999, p. iv). NBAC also recommends that consent forms offer subjects a variety of options, such as the refusal of their biological materials for research, the use of their materials for

anonymous research only, or the use of the biological materials for encoded/encrypted research. While geneticists on the GRAC tended to stress the fact that most people willingly participated in research projects in the hope of positive benefits for their families or society in general, one geneticist acknowledged that her patients were often concerned about what happened to their samples after testing (GRAC minutes, November 3, 1999). A series of focus group discussions around Oregon, commissioned by a non-profit educational organization, identified similar concerns (Davis & Hibbitts, 2000). The GRAC final report does recommend that when informed consent is required under the federal “Common Rule,” that consent should be specifically for genetic research, and not simply a blanket consent that covers testing for clinical and research purposes (GRAC, 2000).

A few members of the committee also attempted to raise the issue of federal gene patenting in relation to the property clause. These members raised their opposition to gene patenting as a reason to retain the property clause. Though Oregon law obviously has no authority over federal patenting policies, some members reasoned that if DNA were treated essentially as property at the federal level, individuals could only truly be protected from misuse of their DNA by declaring it their property. The opposition to patenting and support of the property clause as a temporary solution (in the absence of federal legislation) matches the arguments of George Annas and the proposal for national privacy legislation. In a recent interview, Annas commented on the efforts to remove the property clause in Oregon, referring to the practice of patenting:

That property notion was developed on the basis of the common-sense notion that no one should have greater authority over your own body and DNA than you...The idea that anyone else can own your DNA—like the biotech companies or the researchers— $\ominus$  while you can't strikes me as nonsense. It can't possibly be that everyone else in the world can own my DNA, but I can't. So when researchers at biotech companies complain about the property notion potentially interfering with what they're doing, what they're really balking at is having to go to the trouble of getting explicit authorization from individuals before using their DNA for commercial or research purposes (Compton, 2000, p. 1).

Despite the efforts of OGPAC members to introduce patenting into the debate, the only person who testified before the committee on patenting was a lawyer who supported gene patenting (GRAC minutes, January 5, 2000). Representatives from both OHSU and PhRMA rejected taking up the issue of patenting in the committee, stating that it was a federal issue and was

unrelated to the issue of privacy (GRAC minutes, April 5, 2000).

### The Oregon compromise

While the GRACs final report did recommend eliminating the property clause, it also proposed changes to Oregon's GPA that would make the law more explicit with regard to penalties, discrimination, and obtaining informed consent. The GRAC presented its bill, Senate Bill 114, to the Oregon Senate in January of 2001, and the bill was passed into law in May of 2001 with widespread support from health care and biotechnology interests as well as the consensus opinion of the GRAC. Oregon will still have one of the most comprehensive genetic privacy laws in the country. Important questions, however, are still unresolved. The law protects only those who have a genetic test, not those who seek genetic counseling. The law also does not prevent insurance companies from using family history, or the test results of blood relatives, in determining coverage. The GRACs calls for the creation of another advisory committee to study these questions, as well as the issue of gene patenting. The consumers were successful in getting an agreement that the new committee, if created by the legislature, would include public involvement and education in its activities. However, representatives from the health-care, insurance, and biotechnology industries would still dominate the new committee.

The committee also avoided some deeper questions about informed consent, such as the way barriers of language, culture or class might affect the context in which consent is obtained. The committee also agreed that while a health crisis might be a difficult time for a person to carefully consider risks and benefits, such concerns were beyond the scope of the GRAC (GRAC minutes, 1 December 1999).

Opposition to the bill surfaced from consumer groups, including Oregonians for Genetic Integrity (OGI), an organization that formed specifically to fight the bill. OGI supports individual ownership rights to DNA and opposes patents. They argue that property rights are the best way for individuals to avoid being used in unethical or immoral experiments, such as human cloning (OGI 2001). In his testimony before the judiciary, founder Steve Chase also reasoned that individuals should be allowed to seek profits from research using their DNA. Another member of OGI wrote to a newspaper, “without ownership of our genetic information we will have no way to prevent uses we find unethical once it has been extracted from us. Technology now allows mind-boggling opportunities to violate our sensibilities of right and wrong” (Howard, 2001).

Just as the GRAC finished its report on genetic privacy in Oregon, OHSU announced plans to raise

\$500 million to pursue biotech research made possible by the HGP (*Oregonian*, 26 October 2000, p. D1). The university plans to build a large new facility and hire 300 new scientists. This latest venture suggests why changes to Oregon's genetic privacy legislation are so important to the medical school at this time. It also suggests that the dispute over the ownership of DNA is far from over in Oregon.

### Conclusions: what to do with DNA?

With the development of the biotechnology industry, genes have taken on a (social) life of their own. The commodification of DNA has also met with resistance on the part of research subjects as well as the general public, all potential DNA donors. The construction of DNA as property with commercial value, the identification of the self with DNA, and the objectification of body parts are all necessary to this process of commodification. As the contributors to *The Social Life of Things*, introduced at the beginning of this essay, might have predicted, however, the process of transforming the social meanings of the body, including its most microscopic parts, is uneven and highly contested.

The passionate claims and counter-claims over DNA ownership themselves are noteworthy for several reasons. Proponents of individual property rights in DNA themselves acknowledge the lack of widespread employment and insurance discrimination thus far. Likewise, the fears expressed by biotechnology companies about research subjects scrambling for a share of the profits have thus far not been confirmed. The heated nature of the debate, then, seems to indicate not only the enormous amount of money at stake, but also deep cultural ambivalence about the commodification of the body and its parts. I have argued that those who assert claims of ownership in their own bodies have failed to challenge the inexorable commodification and objectification of the body made possible by the HGP. If fact, the most vocal critics of gene patenting have sometimes played their own role in making genes commodities—by supporting property laws in the body, by sometimes suggesting that we should be able to sell our own DNA, and by emphasizing deterministic assumptions about the DNA as the locus of our identities. Legal scholars argue for or against property rights to the body, for or against gene patenting, but rarely argue against *ever* treating the body or its parts as property. Medical ethicists tend to privilege individual autonomy, many suggesting that individuals should have the autonomy to sell their parts, including their DNA, while arguing rather disingenuously that this would not encourage the commodification of the body. Given the way in which genetics refigures kin and family relations, individual autonomy seems an inappropriate principle to apply here at any

rate. Even rare mutations are shared by family members, raising complicated questions about to whom ownership and use rights would apply (see Finkler, 2000, p. 4). Trapped in a debate over ownership claims, neither side has questioned in a meaningful way assumptions about genetic determinism, or the way in which property claims negate other social meanings of the body.

The debate in Oregon exemplifies this dilemma. PHRMAs representative repeatedly asserted that individuals should not be allowed a property right to their genetic information, since one's privacy should be considered an inalienable right. Yet this contradicts the pharmaceutical industry's patent claims on human DNA. Those who challenge gene patenting claims have found it difficult to do so outside of the property framework, as exemplified by Oregon's "property clause" proponents. If the reaction to genetic privacy legislation in Oregon is any indication, however, the public's ambivalence over the promises of the new genetics, and resistance to the commodification of DNA, will continue.

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