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## WHO OWNS YOUR BODY? A STUDY IN LITERATURE AND LAW

LORI ANDREWS\*

The arts have long inspired law and social policy. Literature, paintings, photographs, songs, and even cartoons have documented social injustices, challenging and sometimes changing the social structure. After Upton Sinclair's novel *The Jungle* revealed the filthy, corrupt conditions of the Chicago meatpacking industry, the resulting public outcry led to the passage of the Meat Inspection Act and the Pure Food and Drug Act of 1906.<sup>1</sup> Within days of Dorothea Lange's publication of one of her photos, "Migrant Mother," in the *San Francisco News* in 1936, the federal government rushed 20,000 pounds of emergency food to the migrant pea-picker community of the woman in the photo. Within a few months, two migrant camps were established for homeless workers.<sup>2</sup>

Usually, the novelist or artist focuses light on a social injustice and the body politic determines what laws need to be in place to restore justice. But in his novel *Next*, Michael Crichton not only provides a riveting tale about the biotechnology industry, complete with disputes over body tissue and efforts to patent human genes, but he also includes a non-fiction appendix, telling policymakers exactly what to do.<sup>3</sup>

At the Institute for Science, Law and Technology (ISLAT) at Chicago-Kent College of Law, we have long undertaken biotechnology-related projects, funded by the National Institutes of Health, the National Science Foundation, the U.S. Department of Energy, and the Robert Wood Johnson Foundation, assessing the impacts of gene patents and analyzing the growing number of legal disputes over body tissue. But the arts did not figure strongly in the mix until, with a grant from the Greenwall Foundation and the aid of co-convenor Joan Abrahamson, we sponsored meetings at the Los Angeles Museum of Contemporary Art and the Salk Institute that

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1. U.S. FOOD & DRUG ADMIN., HISTORY OF THE FDA :THE 1906 FOOD AND DRUGS ACT AND ITS ENFORCEMENT, <http://www.fda.gov/oc/history/historyoffda/section1.html> (last visited Feb. 9, 2008); Ilyse D. Barkan, *Industry Invites Regulation: The Passage of the Pure Food and Drug Act of 1906*, 75 AM. J. PUB. HEALTH 18, 25.

2. Mary Panzer, *Myth Adds Allure to Lange Photo*, CHI. TRIB., Nov. 6, 2002, at T1.

3. MICHAEL CRICHTON, *NEXT* 417-23 (2006).

brought together a small group of novelists, artists, scientists, and law professors.<sup>4</sup> One of the participants was Michael Crichton, who shortly thereafter began work on *Next*.

When *Next* appeared, some reviewers questioned whether the scientific and legal picture Crichton portrayed was an accurate one. As he notes in his essay in this issue, “What I Have Learned from the Reactions to My Books,” even reviewers in scientific journals did not realize he was dealing with technologies that already existed and telling thinly-disguised versions of actual legal cases. How could adequate legal policies be put in place if commentators for the most influential journals and newspapers did not know the basic facts about biotechnology and its impacts on individuals, families, communities and social structures?

In sponsoring a conference entitled “Who Owns Your Body?: Legal and Social Issues in Michael Crichton’s *Next*,” ISLAT brought together lawyers, social scientists, a judge, individuals who had been the subjects of landmark legal cases in the field, and Michael Crichton himself. Participants analyzed the real-life parallels of the fictional events in *Next* and proposed policies for dealing with the controversies the book exposed.<sup>5</sup> The inquiry is a timely one, since disputes over body tissue, genes, and biotechnology patents are finding their way into all areas of law, raising a complex set of legal issues involving torts, crimes, patents, contracts, property law, the Uniform Commercial Code, human research regulations, international law, and more.

The property issues raised by biotechnology came to the fore in *Moore v. Regents of the University of California*.<sup>6</sup> After John Moore’s surgery for hairy cell leukemia, his doctor kept asking him to return from Seattle to Los Angeles to provide samples of blood, sperm, bone marrow, and other tissue.<sup>7</sup> Without Moore’s knowledge or consent, his doctor produced a cell

4. The people who agreed to participate were truly extraordinary—seven were recipients of MacArthur Foundation genius awards (in fields ranging from poetry to physics), one was a Nobel Laureate, one won a National Book Award, one had exhibited her work in the Whitney and Guggenheim, one was the only person to have the number one book, number one television show and number one movie at the same time, one had been awarded three Nebulas (a science fiction award), one was a federal appellate judge, and the others all had been honored in other ways for high achievement in their fields. The members of this group were George Annas, Nigel M. de S. Cameron, Patricia and Paul Churchland, Michael Crichton, Debra Greenfield, Ruth H. Grobstein, Roger Guillemin, Jens Hauser, Neil A. Holtzman, Lewis Hyde, Stacy Ingber, Natalie Jeremijenko, Richard Kenney, Nancy Kress, Hideo Mabuchi, Margaret McKeown, Karl Mihail, Stuart Newman, Richard Powers, Peter Salk and Kim Trang Tran.

5. For more information about the conference, as well as additional information about the issues, see *Who Owns Your Body?*, <http://www.whoownsyourbody.org> (last visited Feb 2, 2009).

6. 793 P.2d 479 (Cal. 1990).

7. *Id.* at 480–81.

line from Moore's tissue, named it the Mo cell line, patented it, and then sold rights to the cell line to a biotechnology firm.<sup>8</sup>

When Moore found out that he was patent number 4,438,032, he felt that his integrity had been violated, his body exploited, and his tissue turned into a product. He said that his doctors had "claim[ed] that my humanity, my genetic essence, was their invention and their property. They viewed me as a mine from which to extract biological material. I was harvested."<sup>9</sup>

When the California Supreme Court considered the issue, it ruled that Moore could not sue for theft of his property—his cells—but that his right to informed consent had been violated. Justice Mosk, in dissent, expressed concern about giving companies "the right to appropriate and exploit a patient's tissue for their sole economic benefit—the right, in other words, to freely mine or harvest valuable physical properties of the patient's body[.]"<sup>10</sup>

Justice Arabian, a participant in the conference that gave rise to this symposium issue, added his concern in his concurring opinion in the *Moore* case. "Does it uplift or degrade the 'unique human persona' to treat human tissue as a fungible article of commerce? Would it advance or impede the human condition, spiritually or scientifically, by delivering the majestic force of the law behind plaintiff's claim?"<sup>11</sup>

But property law is not the only legal domain for these controversies. Tax practitioners are confronted with cases involving people who sell their blood for money. Are those people entitled to a business deduction for the vitamins they take? Can they claim depreciation on their bodies?

When Dorothy R. Garber reported \$9,512.80 in income on her return, the Internal Revenue Service calculated her taxable income at \$96,477.50 after the sale of her rare blood was included.<sup>12</sup> A jury found her guilty of tax evasion, but an appellate court reversed, stating that "[n]o court [had] yet determined whether payments received by a donor of blood or blood components are taxable as income."<sup>13</sup> Margaret Cramer Green, a Florida woman, supported herself by donating her blood plasma.<sup>14</sup> But when she tried to depreciate her body on her tax form, the deduction was disallowed

8. *Id.* at 481–82; John Vidal & John Carvel, *Lambs to the Gene Market*, *GUARDIAN*, Nov. 12, 1994, at 25.

9. Vidal & Carvel, *supra* note 8.

10. *Moore*, 793 P.2d at 515–16 (Mosk, J., dissenting).

11. *Id.* at 497–98 (Arabian, J., concurring).

12. *See United States v. Garber*, 589 F.2d 843, 846 (5th Cir. 1979).

13. *United States v. Garber*, 607 F.2d 92, 97 (5th Cir. 1979) (en banc).

14. *Green v. Comm'r*, 74 T.C. 1229, 1230 (1980).

by the court.<sup>15</sup>

In the contracts field, in *Washington University v. Catalona*,<sup>16</sup> the lure of biotechnology caused a judge to set aside normal contract principles. In that case, thousands of patients gave their body tissue to Dr. Catalona at Washington University after executing a contract—a research informed consent form—that said that the doctor would undertake prostate cancer research on the samples and that the patients could withdraw from the research at any time and destroy the samples.<sup>17</sup> But Washington University realized it could make money by selling the tissue to biotech companies. The university brought suit, claiming the tissue was its property, not the patients'. The patients intervened, attempting to hold the university to its written promises. In a decision later upheld by the Eighth Circuit Court of Appeals,<sup>18</sup> the federal district court symbolically tore up the contract and gave the patients even fewer rights than John Moore had, saying that “the existence of the informed consent forms is inconsequential.”<sup>19</sup>

In criminal law, cases are pending all around the country in the wake of a scheme to plunder dead bodies for their organs, bones and tissue.<sup>20</sup> When a cancer-ridden Alistair Cooke died at age ninety-five, his daughter opted for cremation.<sup>21</sup> Unbeknownst to her, the East Harlem New York Mortuary Service had a deal in place with a tissue procurement service, Biomedical Tissue Services, which stripped Cooke's body of his valuable parts.<sup>22</sup> His bones alone could be sold for \$7,000.<sup>23</sup> But the unwitting recipients were given false information about the age and cause of death of the “donor.”<sup>24</sup> The same thing happened with bones, heart valves, and other tissue from more than 1,000 other people.<sup>25</sup> And many of the recipients, whose doctors thought they were implanting healthy tissue, are now at risk of serious diseases and have turned to the courts.

15. *Id.* at 1238.

16. 437 F. Supp. 2d 985 (E.D. Mo. 2006), *aff'd*, 490 F.3d 667 (8th Cir. 2007).

17. *Id.* at 988, 990.

18. *Washington University v. Catalona*, 490 F.3d 667 (8th Cir. 2007).

19. *Catalona I*, 437 F. Supp. 2d at 998.

20. *See, e.g.*, Press Release, Kings County District Attorney's Office, Kings County District Attorney Charles J. Hynes Announces Sentencing in Tissue Harvesting Case, (June 27, 2008), [http://www.brooklynda.org/press\\_releases/pr\\_jun\\_08.htm#21](http://www.brooklynda.org/press_releases/pr_jun_08.htm#21).

21. Michael Brick, *Alistair Cooke's Bones Were Plundered, His Daughter Says*, N.Y. TIMES, Dec. 23, 2005, at B4.

22. *Id.*

23. *Alistair Cooke's Bones 'Stolen'*, BBC NEWS, Dec. 22, 2005, <http://news.bbc.co.uk/2/hi/americas/4552742.stm>.

24. Brick, *supra* note 21.

25. *US Undertakers Admit Corpse Scam*, BBC NEWS, Oct. 19, 2006, <http://news.bbc.co.uk/2/hi/americas/6064692.stm>.

With living individuals, much of the surreptitious use of their tissue is done to identify and patent genes. Should a gene removed from someone's body be the property of the scientist who removed and sequenced it—or are genes unpatentable products of nature like a mineral found in the ground? A patent on a human gene gives the holder the exclusive rights to use that gene sequence for twenty years. That is how the holder of the patent on a gene sequence related to breast cancer was able to stop a Yale researcher from undertaking breast cancer research.<sup>26</sup> And that is why the holders of patents on gene sequences can charge thousands of dollars in royalties each time a patient's own gene is analyzed to determine if he or she has a predisposition to a disease.<sup>27</sup>

### INJUSTICES IN BODY DISPUTES

The contributors to this symposium issue, all of whom participated in the “Who Owns Your Body?” Conference at IIT Chicago-Kent College of Law, help us understand the scientific and legal challenges raised by *Next*. Michele Goodwin in “Expressive Minimalism and Fuzzy Signals: The Judiciary and the Role of Law” assesses the growing demand, fueled by the biotech industry, for body parts and body tissue. She speculates on why judges have not adequately responded to the challenges raised in the tort sphere and constitutional sphere by the people whose tissue and body parts are used (or into whom body tissue is transplanted). She suggests that courts’ “expressive minimalism” is due to “limited information, ambivalence, or an expectation—hope really—that Congress will demarcate the appropriate boundaries and conduct for biotech actors.” She argues “that market realities already exist in the human body and the judiciary’s intentional ignorance of that will not signal legislative action, nor will it create structural incentives for bad actors to behave differently.”

Julie Burger in “What is Owed Participants in Biotechnology Research?” outlines the ethical and legal principles that underlie the duties researchers owe to individuals who provide their tissue and body parts to be used in biomedical research. She analyzes the extent to which courts, government agencies, and institutions have enforced and upheld these duties and to what extent participants’ rights to control their tissue have been violated. She predicts the effects on participation in research studies if peo-

26. Kimberly Blanton, *Corporate Takeover Exploiting the US Patent System, a Single Company Has Gained Control Over Genetic Research and Testing for Breast Cancer. And Scientists, Doctors, and Patients Have to Play by its Rules*, BOSTON GLOBE, Feb. 24, 2002, Magazine, at 10.

27. For example, Myriad charges \$3000 to sequence two breast cancer genes. Erik Stokstad, *Genetic Screen Misses Mutations in Women at High Risk of Breast Cancer*, 311 SCIENCE 1847 (2006).

ple lose trust in researchers and institutions because promises made to them about the use of their tissue are not kept.

Seth Shulman's article focuses the discussion on the intellectual property ramifications of the fight over the body. In "Upstream Without a Paddle: Gene Patenting and the Protection of the 'Infostructure,'" Shulman places the gene patent controversy in a larger context. He concludes, "Today's privatization of knowledge assets—including genes and genetic information—threatens to choke productivity, magnify inequities, and erode our democratic institutions."

John Conley in "Gene Patents and the Product of Nature Doctrine" assesses the scientific underpinnings of patents on genetic sequences. He applies standard patent law doctrines, including patentable subject matter requirements that forbid patents on products of nature, and raises concerns about the propriety of gene patents.

In his article, "Human Gene Patents: Real Proof of Real Problems?," Timothy Caulfield points out that there are now "thousands of human gene patents in existence (over 40,000 have been issued covering more than 20% of the extant human genome)."<sup>28</sup> He reviews some of the evidence about whether gene patents are interfering with health care and research and asks the provocative question: "How much evidence is needed to justify reform?"

Debra Harry in "Indigenous Peoples and Gene Disputes" adds a refinement to the inquiry. She argues that the impact of gene patents and human tissue policies should be analyzed based not only on the effects on cost, quality and innovation in health care but also on the impact of the policies on individual well-being, religious beliefs, indigenous peoples and the cultural implications of those policies. She also highlights how failure of researchers and research institutions to live up to informed consent can lead to costly battles to regain tissue that was taken or used without consent.

#### AVENUES OF REFORM

While thirty years ago, the topics of this symposium might have been of interest to a narrow group of specialists, Stephen Hilgartner in "Intellec-

28. Timothy Caulfield, *Human Gene Patents: Proof of Problems?*, 84 CHI.-KENT L. REV. 133 (2009) (citing NATIONAL ACADEMY OF SCIENCES, REAPING THE BENEFITS OF GENOMIC AND PROTEOMIC RESEARCH (Stephen A Merrill & Anne-Marie Mazza, eds., 2006); Scott Stern & Fiona Murray, *Do Formal Intellectual Property Rights Hinder the Free Flow of Scientific Knowledge? An Empirical Test of the Anti-Commons Hypothesis* (Nat'l Bureau of Econ. Research, Working Paper No. W11465, 2005).

tual Property and the Politics of Emerging Technology: Inventors, Citizens, and Powers to Shape the Future” demonstrates the rise of social movements challenging intellectual property policies that affect health, information technology, and protection of the knowledge commons. He suggests that the “growing public debate about intellectual property is better understood as a symptom of institutional deficits in democratic decision making about emerging technologies.” He highlights the existence of social activists who might spearhead reform in the areas discussed in this symposium issue. But what policies should they advocate?

Participants in the “Who Owns Your Body?” Conference suggested various avenues for reform. Justice Armand Arabian, who sat on the panel hearing the landmark *Moore* case, suggested a penal approach. He advocated applying criminal laws to the biotechnology and tissue industries to prosecute people who use people’s tissue in unauthorized ways, including acting without the consent of the person from whom the tissue has been taken or his or her next of kin. In her article in this issue, Michele Goodwin suggests that recognizing a person’s own property rights in his or her body would also be appropriate. Julie Burger concludes that the ethical and legal principles of informed consent for participation in research should be enforced as written, rather than subsumed to researchers’ insatiable demand for tissue.

Several participants in the conference advocated eliminating patents on genetic sequences, including Debra Harry, Michael Crichton, and Jonathan Greenberg, whose family’s Canavan gene mutation had been patented without their knowledge or consent. Seth Shulman in his article advocates that genetic sequences should be part of an “IP-free zone.” John Conley suggests a way that could be accomplished by using the existing products of nature and obviousness doctrines in patent law. And by describing in detail the Congressional response to doctors’ patenting surgical procedures and then suing each other, Shulman additionally shows how a legislative ban on genetic sequences could be accomplished.

Symposium participants raised important concerns about how the current practices of health care providers, researchers, and their institutions may be hampering innovation and running roughshod over individual rights. We can only hope that courts and legislatures are as enlightened as the judge in Michael Crichton’s *Next*, who concludes:

Some courts have decided tissue cases by considering the tissues to be trash. Some courts have considered the tissues to be research material akin to books in a library. Some courts consider the tissues to be abandoned property that can be disposed of automatically under certain circumstances, as rental lockers can be opened after a certain time and the



contents of those lockers sold. Some courts have attempted to balance competing claims and have concluded that the claims of society to research trump the claims of the individual to ownership.

Each of these analogies runs up against the stubborn fact of human nature. Our bodies are our individual property. In a sense, bodily ownership is the most fundamental kind of ownership we know. It is the core experience of our being. If the courts fail to acknowledge this fundamental notion, their rulings will be invalid, however correct they may seem within the logic of law.<sup>29</sup>

### CONCLUSION

Michael Crichton found inspiration in medical science beginning in his Harvard Medical School days, when he wrote mysteries under a pen name. As a best-selling author, he alerted us to the next big thing in science (biowarfare research, cloning, nanotechnology), so it is only fitting that he chose the title *Next*.<sup>30</sup> Crichton is often identified as the writer who asked, “Where might the latest scientific development take us?” But also embedded in his works are accurate snapshots of the medical researchers at key points in time and the ethical and legal domain in which they operate.

In Crichton’s first wildly successful techno-thriller, *The Andromeda Strain*, the Department of Defense launched Project SCOOP, a secret mission to collect potential vectors for germ warfare from earth’s upper atmosphere. What they unwittingly captured and brought back, however, was a pathogen that turns blood to powder, wiping out all but two residents of the small desert town where the returning satellite touches down. Five intrepid scientists then collaborated, at great personal risk, in a race to understand the extraterrestrial microbe and to find a cure before all humanity perishes.

Fast forward forty years to Michael Crichton’s *Next*, where medical researchers increasingly act like businessmen rather than scientists. In *Next*, scientists patent genes and block other researchers from using them. They become rich selling people’s tissue and cell lines. Ultimately this impedes the development of cures and prevents people—even the wealthy board member of a biotech company—from getting the treatments they need.

Based on *Next*, if *The Andromeda Strain* were placed into today’s research milieu, the five university scientists charged with saving the world would not accomplish their mission. Instead, they would keep information from each other to preserve their competitive advantage, then try to patent the pathogen.

29. MICHAEL CRICHTON, *NEXT* 394 (2006).

30. *Id.*

Reviewing *Next* in the *Wall Street Journal*, Matt Ridley expressed support for Crichton's advice to policymakers to ban gene patents, to establish clear guidelines for patients' control over research on their tissue samples, but to avoid bans on research (such as bans on embryo stem cell research). "These suggestions are good ones," wrote Ridley. "[T]hey might chafe some biotech companies, but they are essentially pro-market and pro-research."<sup>31</sup> And members of Congress seemed to agree. Two Congressmen, Xavier Becerra, Democrat of California, and Dr. David Weldon, Republican of Florida, introduced the Genomic Research and Accessibility Act<sup>32</sup> to ban the practice of patenting genes found in nature. Just as Upton Sinclair and Dorothea Lange inspired legal policy, so, too, did Michael Crichton.

31. Matt Ridley, *Books: Trouble Helix—The Author of 'Jurassic Park' Turns to the Unleashing of Biotechnology*, WALL ST. J., Dec. 2, 2006, at P8.

32. H.R. 977, 110th Cong. (2007).

