

STP 321 -- BIOETHICS, LAW AND THE LIFE SCIENCES
SPRING 2008 (T-TH 10:10 – 11:40)
TAUBMAN 301

INSTRUCTOR

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COURSE OVERVIEW

Developments in biotechnology and the life sciences have called into question existing policy approaches and the adequacy of instruments dealing with intellectual property, reproduction, health, informed consent and privacy. Rapid changes in science and technology appear to be reconstituting concepts of the self and its boundaries, kinship, ownership, and legal rights and obligations of people in relation to their governing institutions. Through reading primary materials and relevant secondary sources, this course seeks to identify and explore salient ethical, legal, and policy issues—and possible solutions—associated with these developments.

REQUIRED BOOKS (available at the Harvard Coop)

Lori B. Andrews, Maxwell J. Mehlman, Mark A. Rothstein, *Genetics: Ethics, Law and Policy* (St. Paul: West Group, 2002) [**abbreviated below as GELP**]

RECOMMENDED AND OPTIONAL BOOKS (on reserve and for optional purchase)

Sheila Jasanoff, *Designs on Nature: Science and Democracy in Europe and the United States* (Princeton: Princeton University Press, 2005).

Lee Silver, *Remaking Eden* (New York: Perennial, 2002 [1997])

Francis Fukuyama, *Our Posthuman Future* (New York: Picador, 2002)

Richard Lewontin, *It Ain't Necessarily So*, 2nd edition (New York: New York Review of Books, 2000).

ON-LINE READINGS (available at course web site)

**** All books and materials not available on line are available at the KSG library on short-term reserve**

ASSIGNMENTS AND WEIGHTING

50% - Two 8-10 page papers submitted during the term (equally weighted).

25% - Two class presentations with 2-3 page response papers and leading discussion.

25% - Weekly 1-page response papers on the readings.

(A single paper option will be available to students with special permission from the instructor. Weekly response papers will be guided by questions provided by the instructor.)

PLEASE FAMILIARIZE YOURSELF WITH THE ACADEMIC INTEGRITY POLICY

COURSE SYLLABUS

0. OVERVIEW

0. January 29: (Shopping) Overview of Course
GELP, “Scientific Overview”, 16-43.

I. FOUNDATIONS

1. January 31: Biotechnological Utopias

F. S. Collins, et al., “A vision for the future of genomics research,” *Nature* 422:835 – 847.
 (24 April 2003) <http://www.nature.com/nature/journal/v422/n6934/pdf/nature01626.pdf>
 E. Lander, “Array of Hope,” *Nature Genetics*, Supplement, 21 (January 1999), 3-4
 L. Silver, *Remaking Eden*, Ch. 1, “What is Life?”
 M.J. Sandel, “The Case against Perfection,” *Atlantic*, April 2004: 51-62.
 E. Kac, The glowing rabbit, <http://www.ekac.org/gfpbunny.html#gfpbunnyanchor>

2. February 5: Biotechnological Dystopias

F. Fukuyama, *Our Posthuman Future*, Ch. 1, “A Tale of Two Dystopias,” Ch. 5, “Genetic Engineering.”
 P. Rabinow, “Getting to Know You,” *Nature Biotechnology* 20:545-546 (June 2002).
 R. Lewontin, *It Ain't Necessarily So: The Dream of the Human Genome and Other Illusions* (New York: NY Review of Books, 2001), Ch. 5, “The Dream of the Human Genome,” 133-196.
 L. Silver, *Remaking Eden*, Prologue, 1-13.

3. February 7: Genes, Identity, Culture

L. Cavalli-Sforza, *Genes, People, and Languages* (Berkeley: UC Berkeley Press, 2000), Ch. 1, “Genes and History,” 3-32.
 N. Rose, *The Politics of Life Itself* (Princeton: Princeton University Press, 2007), Ch. 5, “Biological Citizens,” 130-154.
 S. Jasanoff, “In the Democracies of DNA: Ontological Uncertainty and Political Order in Three States,” *New Genetics and Society* 24(2):139-155 (2005).

4. February 12: Biomedical Ethics and ELSI

GELP, 83-84.
 P. Singer, “Moral Experts,” *Writings on an Ethical Life* (New York: Harper Collins, 2000), 3-6.
 E. W. Clayton, “Ethical, Legal, and Social Implications of Genomic Medicine,” *New England Journal of Medicine* (2003); 349:562-9, <http://content.nejm.org/cgi/reprint/349/6/562.pdf>.
 A. L. Caplan, “Free the National Bioethics Commission,” *Issues in Science and Technology* (Summer 2003):85-87.
 J. Evans, “Between Technocracy and Democratic Legitimation: A Proposed Compromise Position for Common Morality Public Bioethics,” *Journal of Medicine and Philosophy* 31(3): 213-234 (2006).

II. CONSTITUTING THE GENETIC PERSON

5. February 14: Eugenics

GELP, “Eugenics”, 40-84, esp. *Buck v. Bell*, *Skinner v. Oklahoma*.
 L. Silver, *Remaking Eden*, Ch. 17, “The Virtual Child.”
 J. Holt, “Measure for Measure: The Strange Science of Francis Galton,” *New Yorker*, January 24/31, 2005, 84-90.
 Look at image archive on the American Eugenics Movement, posted by the Cold Spring Harbor Laboratory, available at <http://www.eugenicsarchive.org/eugenics/>

6. February 19: Classifying Persons

GELP, 872-876.
 M. Foucault, *Discipline and Punish* (New York: Vintage, 1979), Part III, Ch. 3 (“Panopticism”), 195-228.
 M. Foucault, *The History of Sexuality*, Vol. 1 (New York: Vintage, 1990 [1976]), 135-145 (“Biopower”).

- A. Lakoff, *Pharmaceutical Reason: Knowledge and Value in Global Psychiatry* (Cambridge: Cambridge University Press, 2005), Ch. 6, "The Segmented Phenotype," 160-177.
- A. Berenson, "Drug Approved. Is Disease Real?" *New York Times*, January 14, 2008, <http://www.nytimes.com/2008/01/14/health/14pain.html?em&ex=1200718800&en=7a8c3b486fb1f949&ei=5087%0A>

7. February 21: Assisted Reproduction and the family

GELP 586-588, 627-636, *Buzzanca*

Davis v. Davis (Tenn, 1992),

http://philosophy.wisc.edu/streiffer/BioandLawF99Folder/Readings/Davis_v_Davis.pdf.

C. Thompson, *Making Parents: The Ontological Choreography of Reproductive Technologies* (Cambridge, MA: MIT Press, 2005), Ch. 4, "Is Man to Father as Woman Is to Mother?" 117-143.

S. Jasanoff, *Designs on Nature: Science and Democracy in Europe and the United States* (Princeton: Princeton University Press, 2005), Ch. 6, "Natural Mothers and Other Kinds," 146-170.

8. February 26: Genetic Enhancement: Clones and Designer Babies

L. Silver, *Remaking Eden*, Part III, "Cloning," 107-152.

A. Buchanan et al., *From Chance to Choice: Genetics and Justice* (Cambridge: Cambridge University Press, 2000), Ch. 5, "Why Not the Best?," 156-203.

L. Silver, *Remaking Eden*, Ch. 18, "The Designer Child," 266-280.

Quintavalle v. Human Fertilisation and Embryology Authority [2002] EWCA Civ 667 (UK),

http://www.courtservice.gov.uk/judgmentsfiles/j1749/quintavalle_v_human_fertilisation.htm

9. February 28: Genes and Sexuality

I. Hacking, Ch. 5, "Kind-making: The Case of Child Abuse," in *The Social Construction of What?* (Cambridge, MA: Harvard University Press, 1999), 125-162.

Bowers v. Hardwick (U.S. 1986),

<http://caselaw.lp.findlaw.com/scripts/getcase.pl?court=US&vol=478&invol=186>,
[edited version].

Lawrence v. Texas (U.S. 2002),

<http://a257.g.akamaitech.net/7/257/2422/26jun20031200/www.supremecourtus.gov/opinions/02pdf/02-102.pdf>, [edited version].

10. March 4: Behavioral Genetics

GELP, 713-734 (esp. cases), 752-756 (Genetic Exceptionalism)

R. Lewontin, Ch. 2, "All in the Genes?" in *Biology as Ideology: The Doctrine of DNA* (New York: Perennial, 1991), 17-38.

G.E. Allen, "Modern Biological Determinism: The Violence Initiative," in M. Fortun and E. Mendelsohn, eds., *The Practices of Human Genetics* (Dordrecht: Kluwer, 1999), 1-23.

S. Jasanoff, "DNA's Identity Crisis," in D. Lazer, ed., *DNA and the Criminal Justice System* (Cambridge: MIT Press, 2004), 337-355.

11. March 6: Genome Diversity Politics

HapMap Project Web Sites:

International HapMap Homepage, <http://www.hapmap.org/>

NIH HapMap page, <http://www.genome.gov/page.cfm?pageID=10001688>

J. Couzin, "New mapping project splits community," *Science* 296:1391-1392 (2002), available at http://biosci.usc.edu/courses/2002-fall/documents/bisc403-nordborg_HapMap.pdf

A. Stockdale and S. F. Terry, "Advocacy Groups and the New Genetics," Ch. 4, in J. S. Alper, et al, *The Double-Edged Helix: Social Implications of Genetics in A Diverse Society* (Baltimore: Johns Hopkins University Press, 2002), 80-101.

J.E. Reardon, "The Human Genome Diversity Project: A Case Study in Co-Production," *Social Studies of Science* 31:357-388 (2001).

III. RIGHTS AND INTRUSIONS

12. March 11: Rights to Life: Abortion, Embryos, Stem Cells

GELP 161-182.

Roe v. Wade, <http://www.foxnews.com/projects/pdf/roevwade.pdf>.

Planned Parenthood v. Casey,

<http://www.law.cornell.edu/supct/html/91-744.ZO.html>.

Center for Genetics and Society, on the California Institute for Regenerative Medicine, <http://www.genetics-and-society.org/policies/california/index.html> (browse links to newspaper articles and under “analysis”).

Look at Harvard Stem Cell Institute website, <http://www.hsci.harvard.edu/index.jsp>.

13. March 13: Testing, Screening, Stigmatizing

GELP 371-374 (newborn screening), 412-426 (predictive testing and counseling), 749-752 (medical privacy), 783-788 (insurance), 849-863 (employment).

D. Beeson, T. Duster, “African-American Perspectives on Genetic Testing,” Ch. 7, in J. S. Alper, et al, *The Double-Edged Helix: Social Implications of Genetics in A Diverse Society* (Baltimore: Johns Hopkins University Press, 2002), 151-174.

J. Couzin, “The Twists and Turns in BRCA’s Path,” *Science*, 302:591-93 (24 October 2003).

S. Parthasarathy, “Regulating Risk: Defining Genetic Privacy in the US and Britain,” *Science, Technology, and Human Values* 9(3):332-352 (2004).

14. March 18: Genetic Surveillance and Criminal Law

GELP, 662-712.

Browse The Innocence Project website, <http://www.innocenceproject.org/>.

Harvey v. Horan, 278 F.3d 370, 380 (4th Cir. 2002), <http://pacer.ca4.uscourts.gov/opinion.pdf/016703R1.P.pdf>.

B. Steinhardt, “Privacy and Forensic DNA Data Banks,” in Lazer, ed., *DNA and the Criminal Justice System*, 173-196.

S. Jasanoff, “Just Evidence: The Limits of Science in the Legal Process,” *Journal of Law, Medicine & Ethics* 34(2):328-341(2006).

15. March 20: Property in Human Biological Materials

GELP 267-293, esp. *Moore v. Regents of the University of California*.

J. Boyle, Ch. 9, “Spleens,” in *Shamans, Software and Spleens* (Cambridge, MA: Harvard University Press, 1996).

H. Landecker, “Between Beneficence and Chattel: The Human Biological in Law and Science,” *Science in Context* 12:203-225 (1999).

R. Skloot, “Taking the Least of You,” *New York Times Magazine*, April 16, 2006,

<http://www.nasw.org/users/skloot/TakingTheLeast.pdf>

J. Kaiser, “Court Decides Tissue Samples Belong to University, Not Patients,” *Science* 312(5772):346 (April 21, 2006), <http://www.sciencemag.org/cgi/content/full/312/5772/346>

M. Crichton, “Bodysnatchers 2006,” *Wall Street Journal*, December 2006,

<http://www.michaelcrichton.net/essay-wsj-bodysnatchers.html>

**** [1st paper due in class: 8-10 pages] ****

[Spring Break: March 25 and 27]

IV. MONEY, MARKETS, PROPERTY**16. April 1: Visions of Progress**

S. Jasanoff, *Designs on Nature*, Ch. 9, “The New Social Contract,” 225-246.

V. Rabeharisoa and M. Callon, “The involvement of patients in research activities supported by the French Muscular Dystrophy Association,” in S. Jasanoff, ed., *States of Knowledge: The Co-Production of Science and Social Order* (London: Routledge, 2004), 234-253.

HFEA Policy Statement on Eggs for Research, February 2007, <http://www.hfea.gov.uk/en/1506.html>

National Bioethics Advisory Commission, Ethical and Policy Issues in Research Involving Human Participants, Appendix C, 151-160

<http://bioethics.georgetown.edu/nbac/human/overvoll.pdf>

17. April 3: Science and (Private) Money

GELP 233-236, 263-269.

D. Greenberg, *Science, Money and Politics* (Chicago: University of Chicago Press, 2001), Ch. 22, "The Ethical Erosion of American Science," 348-364.

E. Press and J. Washburn, "The Kept University," *Atlantic Monthly* (March 2000):39-54,

S. Krinsky, "Conflict of Interest Policies in Science and Medical Journals: Editorial Practices and Author Disclosures" (with L.S. Rothenberg). *Science and Engineering Ethics* 7 (April 2001):205-218, available at <http://www.tufts.edu/~skrimsky/sciethics.htm>

W. Lepkowski, "Biotech's OK Corral," *Science and Policy Perspectives* 13 (9 July 2002), <http://www.cspo.org/ourlibrary/documents/060902.html>

18. April 8: Patenting Life

GELP 202-233, esp. *Diamond v. Chakrabarty*, *Amgen v. Chugai*, *Madey v. Duke University*

S. Jasanoff, *Designs on Nature*, Ch. 8, "Making Something of Life," 203-224.

President and Fellows of Harvard College v. Canada (Commissioner of Patents), [2002] 4 S.C.R. 45, available at <http://reports.fja.gc.ca/en/1998/1998fc22348.html/1998fc22348.html.html>

19. April 10: Intellectual Property and Technology Transfer

P. Rabinow, *Making PCR: A Story of Biotechnology* (Chicago: University of Chicago Press, 1996) 19-45.

A. Rai, R. Eisenberg, "Bayh-Dole Reform and the Progress of Biomedicine," *Law and Contemporary Problems* 66 (2003):289-314,

<http://www.law.duke.edu/journals/lcp/downloads/LCP66DWinterSpring2003P289.pdf>

Commission on Intellectual Property Rights (UK), *Integrating Intellectual Property Rights and Development Policy* (September 2002), Ch. 4, "Traditional Knowledge and Geographical Indications," 73-93, available at http://www.iprcommission.org/papers/pdfs/final_report/Ch4final.pdf

M. Crichton, "This Essay Breaks the Law," *New York Times*, March 19, 2006,

<http://www.michaelcrichton.net/essay-nytimes-thisessaybreaksthelaw.html>

20. April 15: Biobanks: Uses and Abuses

GELP, 706-712, *Mayfield*.

H. Rose, *The commodification of bioinformation: the Icelandic Health Sector Database*. London: Wellcome Trust (2001), available at

<http://www.wellcome.ac.uk/assets/WTD003281.pdf>

J. Kaiser, "Population Databases Boom, From Iceland to the US," *Science* 298 (2002):1158-61, available at

http://www.genomics.ee/files/artiklid/science_08_11_02.pdf

MANNVERND [Association of Icelanders for Ethics in Science and Medicine] Website,

<http://www.mannvernd.is/english/>.

D. Winickoff, R. Winickoff, "The Charitable Trust Model for Genomic Biobanks," *New England Journal of Medicine* 349 (18 Sept. 2003):1180-4, available at <http://content.nejm.org/cgi/reprint/349/12/1180.pdf>

D. Caruso, "Someone (Other Than You) May Own Your Genes," *New York Times*, January 28, 2007,

http://www.nytimes.com/2007/01/28/business/yourmoney/28reframe.html?_r=1&scp=1&sq=hilgartner&oref=slogin

21. April 17: Bioprospecting and Indigenous Knowledge

D. Takacs, *The Idea of Biodiversity: Philosophies of Paradise* (Baltimore: Johns Hopkins University Press, 1996), Ch. 6, "Costa Rica's National Institute of Biodiversity," 288-308.

C. Hayden, "From Market to Market: Bioprospecting's Idioms of Inclusion," *American Ethnologist* 30(3):359-371 (2003).

J. Pomfret and D. Nelson, "In Rural China, a Genetic Mother Lode," *Washington Post*, December 20, 2000, A01.

V. BIOTECH AND GLOBAL GOVERNANCE

22. April 22: Agricultural Biotechnology: Transnational Controversies

J. Lassen, et al., "Testing times – the reception of Roundup Ready Soya in Europe," Ch. 10 in Martin W. Bauer and George Gaskell, eds., *Biotechnology: The Making of a Global Controversy* (Cambridge, Cambridge University Press, 2002), 279-312.

S. Jasanoff, *Designs on Nature*, Ch. 4, "Unsettled Settlements," 94-118

"The Academic Experts' Brief for the WTO GMO Dispute: A Summary." *Amicus Curiae* brief to the disputes resolution panel on the *Biotech Products (EC: Measures affecting the Approval and Marketing of Biotech products)* case, available at

[http://www.genewatch.org/article.shtml?als\[cid\]=507728&als\[itemid\]=531320](http://www.genewatch.org/article.shtml?als[cid]=507728&als[itemid]=531320)

Monsanto Canada Inc. v. Schmeiser, [2004] 1 S.C.R. 902, available at

http://www.lexum.umontreal.ca/csc-scc/en/pub/2004/vol1/html/2004scr1_0902.html.

24. April 24: Biotechnology and the Politics of Development

Commission on Intellectual Property Rights (UK), *Integrating Intellectual Property Rights and Development Policy* (September 2002), Ch. 1, "Intellectual Property and Development," 11-20, available at http://www.iprcommission.org/papers/pdfs/final_report/Ch1final.pdf

V. Shiva, "The Golden Rice Hoax: When Politics Replaces Science," October 26, 2000, <http://members.tripod.com/~ngin/11.htm>

G. Conway, Letter to Doug Parr, Greenpeace, January 22, 2001, http://www.biotech-info.net/conway_greenpeace.pdf

GM World View (interactive feature on *Nature Reviews Genetics*)

<http://www.nature.com/nature/focus/gm/map.html>

S. Jasanoff, "Biotechnology and Empire: The Global Power of Seeds and Science," *Osiris* 21(1):273-292 (2006).

25. April 29: The WTO, Intellectual Property, and Pharmaceuticals

Commission on Intellectual Property Rights (UK), *Integrating Intellectual Property Rights and Development Policy* (September 2002), http://www.iprcommission.org/graphic/documents/final_report.htm; see Ch. 2, "Health," 29-56; Ch. 6, "Patent Reform," 111-136; Ch. 8, "International Architecture," 155-170. *Patently Ambitious: The Global Ambitions of India's Biggest Drug Firms*, *The Economist* (6 September 2003):56.

H. Varmus, et al., "Grand Challenges in Global Health," *Science*, 302(2003):398-9.

The International Centre for Trade and Sustainable Development (ICTSD), Doha Round Briefing Series (August 2003), http://www.ictsd.org/pubs/dohabriefings/cancun_updates/V2_05_IPRs.pdf

A. Gentleman, "Setback for Novartis in India Over Drug Patent," *New York Times*, August 7, 2007, <http://www.nytimes.com/2007/08/07/business/worldbusiness/07drug.html?scp=2&sq=glivec+patent>

VI. WRAP UP

26 May 1: The Human Genome: Whose Project?

Fukuyama, *Posthuman Future*, Ch. 10, "The Political Control of Biotechnology," and Ch. 12, "Policies for the Future."

Silver, *Remaking Eden*, Epilogue, 281-294.

B. J. Strasser, "Who Cares About the Double Helix," *Nature* 422 (24 April 2003): 803-804.

Universal Declaration on the Human Genome and Human Rights, 1997, http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html

Council of Europe, Protection of the human genome, Recommendation 1512 (2001)[1], <http://assembly.coe.int/Documents/AdoptedText/ta01/EREC1512.htm>

G. Annas, Mapping the Human Genome and the Meaning of Monster Mythology, *Emory law Journal* 39(3) (1990)

Indigenous Peoples Council on Biocolonialism, *Indigenous Research Protection Act*, at <http://www.ipcb.org/publications/policy/files/irpa.html>

**** [2nd paper due in class: 8-10 pages] ****