

GENETICS, DISABILITY AND THE LAW

Robert S. Olick, J.D., Ph.D.

Meera Adya, J.D., Ph.D.

Spring 2009

Mondays, 5-8 pm

2507 Setnor

Prerequisites: Open to medical, health professions, graduate and graduate nursing students, graduate and law students; others with permission of the instructor.
Prerequisites – Nursing – completion of BSN and prior health care ethics course; SU College of Law – completion of first year courses.

Course credits: 3

Course summary: This seminar course studies the challenging questions that arise at the intersection of genetics, ethics, disability and law. A focus of the course will be to explore how genetic diagnosis and information influences our understanding of disability; the ethical and social issues raised and the choices presented; and the legal rules that may apply to particular situations. We will begin with an introduction and overview of genetics, ethics, law and society. Topics include ethical, legal and social issues surrounding genetics in reproductive medicine, prenatal diagnosis, pre-implantation diagnosis; deciding for disabled newborns; eugenics and non-voluntary sterilization; genetic privacy; genetic discrimination in employment and health insurance; and genetic research such as with stored tissues.

Course objectives: Upon completion of the course students will be able to:

- Identify ethical issues at the intersection of genetic diagnosis and disability
- Understand and articulate ethical arguments on the various sides of these issues
- Identify relevant laws and legal rules addressing such issues as disability discrimination, reproductive choice, treatment of disabled newborns, genetic privacy and genetic research.

About the instructors: Robert S. Olick, J.D., Ph.D., is associate professor in the Center for Bioethics and Humanities, SUNY Upstate Medical University. Meera Adya, J.D., Ph.D., is Director of Research, Burton Blatt Institute, Syracuse University.

Topics and assigned materials: See attached syllabus.

Course structure and assignments: This is a seminar-style course with a mix of lecture and group discussion. Students will be expected to make presentations on assigned topics and materials and to take the lead in classroom discussion. There will be several guest

lectures. Students will be graded on class participation (50%), in-class presentations (20%) and a paper of approximately 10-15 pages in length (30%).

Evaluation: Students' work will be graded according to the grading scale at their home institution and any other applicable rules. Students will be held to a lesser standard of knowledge with respect to specialized disciplines that are not their own (e.g., Upstate medical students will not be expected to understand and articulate the law with the same facility as SU law students).

Class policies: Attendance of all sessions is required. An excused absence may be granted if the student communicates the need to miss class prior to the session. A pattern of absences or late assignments will result in a grade penalty or make-up work.

Syllabus

Texts and readings

- Philip Kitcher, *The Lives to Come: The Genetic Revolution and Human Possibilities* (Touchstone, 1997).
- Selected readings and cases (see weekly assignments)

Jan. 12, 2009 Introduction and Overview; Genes, Disability and Society

- Kitcher, chapter 1.
- Maureen Glabman, "Genetic Testing: Major Opportunity, Major Problems," *Managed Care* (November 2006).
- Michael S. Victoroff, "Roll over, Beethoven – your genetic profile's in," *Managed Care* (November 2006).

Jan. 19 No class. Martin Luther King, Jr. day.

Jan. 26 The Science and Ethics of Genetics (Guest Lecture, Robert Roger Lebel, M.D.)

Kitcher, chapters 2 and 3.

Sign-up for class presentations

Genetic Privacy and Discrimination

Feb. 2 Am I my Genes?

- Film, GATTACA – viewed in class.
- Kitcher, chapter 6.
- National Partnership for Women & Families on behalf of the Coalition for Genetic Fairness, "Faces of Genetic Discrimination:

How Genetic Discrimination Affects Real People” (July 2004), available at www.geneticalliance.org/ksc_assets/documents/facesofgeneticdiscrimination.pdf

Feb. 9 Health Insurance and Access to Care: Actuarial Fairness or Unfair Discrimination?

- Robert J. Pokorski, “Use of Genetic Information by Private Insurers,” in T. Murphy and Marc Lappe, eds., *Justice and the Human Genome Project* (Univ. of Cal. Press, 1994), 91-109.
- Norman Daniels, “The Genome Project, Individual Differences, and Just Health Care, in T. Murphy and Marc Lappe, eds., *Justice and the Human Genome Project* (Univ. of Cal. Press, 1994), 110-132.
- Louise Slaughter, “The Genetic Information Nondiscrimination Act: Why Your Personal Genetics are Still Vulnerable to Discrimination,” *Surg. Clin N Am* 88 (2008): 723-38.
- Kathy L. Hudson, M.K. Holohan and Francis S. Collins, “Keeping Pace with the Times – The Genetic Information Nondiscrimination Act of 2008,” *New England Journal of Medicine* 358 (June 19, 2008): 2661-2663.
- Anita L. Allen, “Genetic Privacy: Emerging Concepts and Values,” in Mark A. Rothstein, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (Yale Univ. Press, 1997), 31-59.

Feb. 16 Genes in the Workplace

- Robert S. Olick, “Genes in the Workplace: New Frontiers for ADA Law, Policy and Research,” in Peter Blanck, ed., *Employment, Disability, and the Americans with Disabilities Act: Issues in Law, Public Policy and Research* (Northwestern Univ. Press, 1999), 285-314.
- Meera Adya and Brian Bornstein, “Genetic Information and Discrimination in Employment: A Psycho-Legal Perspective,” *William Mitchell Law Review* 32 (1): 265-288.
- The Burlington Northern case
 - EEOC SETTLES ADA SUIT AGAINST BNSF FOR GENETIC BIAS, April 18, 2001, <http://www.eeoc.gov/press/4-18-01.html>
 - EEOC AND BNSF SETTLE GENETIC TESTING CASE UNDER AMERICANS WITH DISABILITIES ACT, May 8, 2002, <http://www.eeoc.gov/press/5-8-02.html>

Genetic Testing: From Eugenics to Designer Babies

Feb. 23

Prenatal Diagnosis and Disabled Newborns

- AMA Council on Ethical and Judicial Affairs, “Ethical Issues Related to Prenatal Genetic Testing,” *Archives of Family Medicine* 3 (July 1994).
- Erik Parens, “The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations,” *Hastings Center Report*, supp. (Sept.-Oct. 1999): S1-S22.
- Bonnie Steinbock, “The Logical Case for ‘Wrongful Life,’” *Hastings Center Report* 16 (Apr. 1986): 15-20.
- Loretta M. Kopelman, “Are the 21-Year-Old Baby Doe Rules Misunderstood or Mistaken,” *Pediatrics* 115 (2205): 797-802.

Mar. 2

Eugenics and Nonvoluntary Sterilization

- History of Eugenics in New York State, materials distributed in class.
- Cold Spring Harbor Laboratories, Dolan DNA Learning Center, <http://www.eugenicsarchive.org>
- Kitcher, chapters 5, 8.
- *Buck v. Bell*, 274 U.S. 200 (1927).
- *Skinner v. Oklahoma*, 316 U.S. 535 (1942).

Mar. 9

No class; SU Spring break

Mar. 16

Children of Choice; Pre-implantation Genetic Diagnosis (PGD); Genetic Enhancement

- Kitcher, chapter 14.
- Sarah E. Stoller, “Why We Are Not Morally Required to Select the Best Children: A Reply to Savulescu,”

Genetic Research

Mar. 23

John Moore’s Spleen; Who Owns My Genes?

- Robert F. Weir and Robert S. Olick, *The Stored Tissue Issue: Biomedical Research, Ethics, and Law in the Era of Genomic Medicine* (Oxford Univ. Press, 2004), chapter 7.
- *Moore v. Regents of the University of California*, 793 P.2d 479 (1990).

Mar. 30

The Federal Policy, IRBs, and Stored Tissue Research

- Robert F. Weir and Robert S. Olick, *The Stored Tissue Issue: Biomedical Research, Ethics, and Law in the Era of Genomic Medicine* (Oxford Univ. Press, 2004), chapter 6.
- *Greenberg v. Miami Children's Hosp. Research Institute*, 264 F. Supp. 2d 1064 (S.D. Fla. 2003).

April 6 Genetics, Disability and Human Rights

- The UN Convention on the Rights of Persons with Disabilities (2006).
- Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Oviedo, 4.IV.1997.
- Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes, Strasbourg, 27.XI.2008.
- Anita Silvers and Michael A. Stein, "Human Rights and Genetic Discrimination: Protecting Genomics' Promise for Public Health," *Journal of Law, Medicine, and Ethics* 31 (3): 377-389.

April 13 Topic of choice: Genetics and public health? newborn screening? Case studies on short stature and choosing deafness? Other?

Readings to be determined

April 20 Student Presentations

April 27 Student Presentations