

EXTD 203: Ethical and Social Issues in Genetics
Fall 1996, Tuesday: 7:00-9:20 p.m.
Science Center, Rm. 274

Adrienne Asch (email: aasch)
Office Hours: Thurs. 10a.m.-1p.m. & by appointment
Teaching Office: Founders 217a, x3248
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COURSE READINGS:

Readings for this course are drawn from two sources: articles placed on Reserve (R); and the following books available at the bookstore (B):

Annas, G.J. and Elias, S. (Eds.) (1992). Gene Mapping. NY: Oxford University Press.

Shelley, Mary. Frankenstein.

Weir, R.F., Lawrence, S.C., and Fales, E. (Eds.) (1994). Genes and Human Self Knowledge: Historical and Philosophical Reflections on Modern Genetics. University of Iowa Press.

Students are responsible for all of the readings listed for the week, except for those under the heading "student reports." I will explain the use of the "Student Report" items in plenty of time for each student to select readings from those listed for papers and class discussions that use these selections. See Course Requirements below.

COURSE REQUIREMENTS:

1. Attendance and active participation in class discussions, requiring that students be ready to discuss the readings the day they are listed on the syllabus. Given the discussion-format of the class, your involvement is crucial for everyone's learning. I will take attendance and will expect students to be absent rarely, if at all. Attendance, participation, and a group oral presentation will be 20 percent of the final grade.
2. Written assignment due October 11th and explained during first weeks of class (15 percent).
3. Written assignment due November 15th, that will include readings listed in "Student Reports" sections of syllabus (30 percent).

4. Analysis of one controversial question in a 10-page paper due last day of exam period. Paper topics must be approved by November 26th. Examples of appropriate topics will be provided, but students may propose others (35 percent).

OFFICE HOURS:

10:00 a.m. to 1:00 p.m. Thursdays and by appointment. I can arrange other times for people who cannot use these hours, or in situations where I must cancel office hours. I usually am not available Mondays or Tuesdays and cannot meet with people before class time on Tuesday evening.

CLASS TOPICS AND READINGS

Unit I: General Introduction to Issues in Genetics

September 10: Introduction and Overview.

Note: I want to set up fifteen-minute meetings with each of you during the first three weeks of the term, so please make sure to arrange a time to visit with me.

September 17: Discussion of Mary Shelley's Frankenstein.

Guest Lecture: Jim Noggle, English Department. This class meeting will take place at my home, 666 Washington Street, 8 Horton House, with refreshments provided.

Shelley, M. Frankenstein. (B)

Annas, G. and Elias, S. (1992). "The Major Social Policy Issues Raised by the Human Genome Project" in Annas, G. and Elias, S. (Eds.). Mapping Our Genes: Using Law and Ethics as Guides. NY: Oxford University Press, 3-17.

(B)

September 24: Basic Genetics.

Guest Lecture: Emily Buchholtz, Biological Sciences Department.

Mader, S.S. (1990). Human Biology, second edition.

Dubuque, IA: Wm. C. Brown Publishers. Part 5: Human Inheritance, 361-412. (R)

October 1: Thinking About Ethical and Social Issues in Genetics; analyzing moral problems raised by genetic research; understanding the problems raised by doing any type of scientific research.

Arras, J.D. and Steinbock, B. (1995). "Introduction: Moral Reasoning in the Medical Context," in Arras, J. and Steinbock, B. (Eds.). Ethical Issues in Modern Medicine, 4th edition. Mountain View, CA: Mayfield Publishing Co., 1-39. (R)

Proctor, R. (1991). Value Free Science? Cambridge, MA: Harvard University Press. Introduction, 1-13. (R)

McKusick, V.A. (1992). "The Human Genome Project: Plans, Status, and Applications in Biology and Medicine," in Annas and Elias, 18-44. (B)

October 8: History of Eugenics.

"Victims of the Past," 30-minute film made by Goebbels' Ministry of Propaganda in 1937. This film portrays the Nazi version of "genetic counseling."

King, Patricia A. (1992). "The Past as Prologue: Race, Class, and Gene Discrimination," in Annas and Elias, 94-114. (B)

Kevles, D.J. (1992). "Out of Eugenics: The Historical Politics of the Human Genome," in D.J. Kevles and L. Hood (Eds.). The Code of Codes: Scientific and Social Issues in the Human Genome Project. Cambridge, MA: Harvard University Press, 3-36. (R)

Paul, D. (1994). "Eugenic Anxieties, Social Realities, and Political Choices," in Carl F. Cranor (Ed.) Are Genes Us? The Social Consequences of the New Genetics. New Brunswick, NJ: Rutgers University Press, 142-154. (R)

Annas, G. and M.A. Grodin (Eds.) (1992). The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation. NY: Oxford University Press. The following sections (R):

The Nuremberg Code, 2.

Annas and Grodin, "Introduction," 3-11.

Proctor, Robert N. "Nazi Doctors, Racial Medicine, and Human Experimentation," 17-31.

Caplan, Arthur. "The Doctors' Trial and Analogies to the Holocaust in Contemporary Bioethical Debates," 258-275.

October 11: Assignment 1 due.

October 15: The Nature-Nurture Debate.

Rowe, D. (1994). The Limits of Family Influence: Genes, Experience and Behavior. NY: Guilford Press. Introduction, 1-6; Chapter 2, 29-56. (R)

Wright, L. (1995). "Double Mystery," New Yorker, August 1995, p. 44-62. (R)

McGue, M., and Lykken, D.T. (1991). "Genetic Influence on Risk of Divorce," Psychological Science, Vol. 3, 368-373. (R)

"Scientific and Research Issues," Glayde Whitney, 946-954; "Philosophical and Ethical Issues," Richard A. Shweder, 954-960. Both are found in the "Genetics and Human Behavior" section of Warren T. Reich, ed. Encyclopedia of Bioethics (EOB) NY: Simon and Schuster Macmillan. (R)

Alper, J.S. and Natowicz, M.R. (1993). "On Establishing the Genetic Basis of Mental Disease." Trends in Neurosciences, Vol. 16, No. 10, 387-389. (R)

Billings, P.R., Beckwith, J., Alper, J.S. (1992). "The Genetic Analysis of Human Behavior: A New Era?" Social Science and Medicine, Vol. 35 No. 3, 227-238. (R)

Unit II: Selecting Children's Characteristics

October 22: Ideas of Kinship, Heredity, and Some Modern Implications.

Guest Lecture: Faith Ferguson, Sociology Department.

Baran, A. and Pannor, R. (1989). "Who Is My Father?" and "My Genes Should Not Be Reproduced," in Lethal Secrets: The Shocking Consequences of Unsolved Problems of Artificial Insemination. New York: Warner Books, 54-73; 99-108. (R)

Weston, K. (1995). "Forever is a Long Time: Romancing the Real in Gay Kinship Ideologies," in Yanagisako, S. and Delancy, C. (Eds.) Naturalizing Power: Essays in Feminist Cultural Analysis. NY: Routledge, 87-110. (r)

October 29: Prenatal Diagnosis and Parenthood: Who uses the technology? Why? What is the process?

- "Human Development from Fertilization to Birth," C. Grobstein, in "Fetus" section of EOB, 847-851. (R)
- "Preimplantation Embryo Diagnosis," Alan H. Handyside, 985-986; "Carrier Screening," A. Cao, 993-995. Both selections are in the "Genetic Testing and Screening" section of EOB. (R)
- "Practice of Medical Genetics," K. Berg, in the "Medical Genetics" section of EOB, 1646-1652. (R)
- King, P. (1994). "Ethics and Reproductive Genetic Testing: The Need to Understand the Parent-Child Relationship," in Rothenberg, K.H. and Thomson, E.J. (Eds.). Women and Prenatal Testing: Facing the Challenges of Genetic Technology. Columbus: Ohio State Univ. Press, 98-104. (R)
- Rothman, B. K. (1994). "The Tentative Pregnancy: Then and Now," in Rothenberg and Thomson, 260-270. (R)
- Rapp, R. (1994). "Women's Responses to Prenatal Diagnosis: A Sociocultural Perspective on Diversity," in Rothenberg and Thomson, 219-233. (R)
- "Practice of Genetic Counseling," B. Biesecker, in "Genetic Counseling" section of EOB, 923-927. (R)
- "National Society of Genetic Counselors Code of Ethics" (Appendix A) (1993), in D.M. Bartels, B.S. LeRoy, A.L. Caplan (Eds.) Prescribing Our Future: Ethical Challenges in Genetic Counseling. NY: Aldine De Gruyter, 169-172. (R)
- Rapp, R. (1984). "XYLO: A Story" in Arditti, R., Klein, D. and Minden, S. (Eds.). Test-Tube Women: What Future for Motherhood? Boston: Pandora Press, 313-328. (R)
- Carney, C. (1994). "Genes and Osteogenesis Imperfecta," in Weir, 63-66. (B)
- Panzarino, C. (1990, October-November). "What is Choice, and Who is Choosing?" Roll Call, 6-7. (R)
- Karuth, D. (1982). "If I Were a Car, I'd be a Lemon," in Brightman, A. (Ed.) Ordinary Moments: The Disabled Experience. Baltimore: University Park Press, 9-31. (R)
- Berube, M. (December 1994). "Life as We Know It: A Father, a Son, and Genetic Destiny." Harper's Magazine, 41-51. (R)

Ackerley, M. (1985). "False Gods and Angry Prophets" and "The Loneliness of the Long-Distance Swimmer," in Turnbull, H.R. and Turnbull, A.P. (Eds.) Parents Speak Out: Then and Now. Columbus, OH: Charles E. Merrill Publishing Company, 23-38. (R)

Massie, R. and Massie, S. (1985). Journey. New York: Knopf. Chapters 16 and 18. (R)

Massie, R. (1985). "The Constant Shadow," in Hobbes, N. and Perrin, J. (Eds.). Issues in The Care of Children with Chronic Illness. San Francisco: Jossey-Bass Publishers, 13-23. (R)

Student Reports:

Each student should select one of the 3 options below:

- I. one other chapter from Brightman, A. (Ed.) Ordinary Moments (R)
- II. one selection from Part One of Turnbull and Turnbull, Parents Speak Out (R)
- III. Ferguson, P.M. and Ferguson, D.L. (May 1996). "Communicating Adulthood: The Meanings of Independent Living for People with Significant Cognitive Disabilities and Their Families." Topics in Language Disorders, 52-67. (R);

Phillips, M.J. (1990). "Damaged Goods: Oral Narratives of the Experience of Disability in American Culture." Social Science and Medicine, Vol. 30, No.8, 849-857. (R); and

Goode, B. "'It's Been a Struggle': Her Own Story," in Dybwad, G. and Bersani, H. (Eds.). New Voices: Self Advocacy by People with Disabilities. Brookline Books, 37-50. (R)

November 5: Arguments for and Against Prenatal Diagnosis. Critiques of the practice of prenatal diagnosis and of genetic counseling, and critiques of the critiques.

Shaw, M. (1984). "To Be or Not to Be? That Is the Question." American Journal of Human Genetics. Vol. 36, 1-9. (R)

Asch, Adrienne (1989). "Reproductive Technology and Disability," in Cohen, S. and Taub, N. (Eds.). Reproductive Laws for the 1990s. Clifton, NJ: Humana

Press, 69-95. (Stop once you get to the section, "Time Limits on Abortion.") (R)

Purdy, L. (1995). "Loving Future People," in Callahan, J.C. (Ed.) Reproduction Ethics and the Law: Feminist Perspectives. Indianapolis: University of Indiana Press, 300-330. (R)

Burr, C. K. (1985). "The Impact of the Chronically Ill Child on the Family," in Hobbes, N. and Perrin, J. (Eds.). Issues in the Care of Chronically Ill Children, 24-40. (R)

Wertz, D. (1992). "How Parents of Affected Children View Selective Abortion," in Holmes, H. (Ed.). Issues in Reproductive Technologies, I. NY: Garland Publishers, 161-192. (R)

Caplan, A. (1993). "Neutrality is not Morality: The Ethics of Genetic Counseling," in Bartels, D.M. et. al. (Eds.). Prescribing Our Future: Ethical Challenges in Genetic Counseling. NY: Aldine de Gruyter, 149-165. (r)

Student Reports:

Saxton, M. (1984). "Born and Unborn: the Implications of Reproductive Technologies for People with Disabilities," in Arditti, R. (Ed.) Test-Tube Women, 298-313. (R)

Botkin, J.R. (1995, September-October). "Fetal Privacy and Confidentiality," Hastings Center Report, 32-39. (R)

Wertz, D. and Fletcher, J. (1993). "A Critique of Some Feminist Challenges to Prenatal Diagnosis," Journal of Women's Health, 2:2, 173-188. (R)

November 12: Knowing Your Own Genetic Future?

"Genetic Predisposition and the Human Genome Project: Case Illustrations of Clinical Problems": PART I by Ray White; PART II by C. Thomas Caskey, in Annas and Elias, 173-185. (B)

Macklin, R. "Privacy and Control of Genetic Information," in Annas and Elias, 157-172. (B)

Geller L.N., Alper, J.S., Billings, P.R., Barash, C., Beckwith, J., and Natowicz, M.R. (1996). "Individual, Family, and Societal Dimensions of Genetic

Discrimination: A Case Study Analysis," Science and Engineering Ethics. Vol. 2, Issue 1, 71-88. (R)

Biesecker, B. (1993). "Genetic Counseling for Families with Inherited Susceptibility to Breast and Ovarian Cancer." Journal of the American Medical Association. Vol. 269, 1970-1974. (R)

Lerman, C. and Croyle, R. (1994). "Psychological Issues in Testing for Breast Cancer Susceptibility." Archives of Internal Medicine. Vol. 154, 609-616. (R)

Geller, G. et. al. (1995, December). "Informed Consent and BRCA1 Testing," Nature Genetics, Vol. 11, 364. (R).

November 15: Assignment 2 due.

November 19: Case Study in Behavioral Genetics: Genetics and Violence.

Science, Vol. 264, June 17, 1994. (R)

Politics and the Life Sciences, Vol. 15, No. 1, Spring 1996.
"Symposium: Genetics and Crime," 83-110. (R)

Alper, J.S. and Beckwith, J. (1993). "Genetic Fatalism and Social Policy: The Implications of Behavior Genetics Research," Yale Journal of Biology and Medicine, Vol. 66, 511-524. (R)

November 26: Genetics and Self-understanding.

Two groups will present prepared presentations on facets of this material as part of the class participation requirement; the groups will be selected and arranged during the semester and will have the chance to meet with me as part of the preparation.

"Genetics and Human Self-Understanding," A. Flew, in EOB, 961-967. (R)

Shuster, E. (1992). "Determinism and Reductionism: A Greater Threat Because of the Human Genome Project?" in Annas and Elias, 115-127. (B)

Parens, E. (1996, July-August). "Taking Behavioral Genetics Seriously," Hastings Center Report, Vol. 26, No.4, 13-22. (R)

From Weir's Genes and Human Self Knowledge (B):

Brock, D.W. "The Human Genome Project and Human Identity," 18-33.

Ruse, M. "Knowledge in Human Genetics: Some Epistemological Questions," 34-45.

Butchvarov, P. "Some Concerns about Self-Knowledge and the Human Genome Project," 46-48.

Carroll, W.E. "Reductionism and Genetics: A Response," 49-52.

Fales, E. "The Human Genome Project and Epistemology," 53-58.

Cates, D.F. "Commentary on Genetic Knowledge and Self-Understanding," 59-62.

December 2: Ethics of Genetic Research.

Groups of students will prepare presentations on this material (see note for November 26th).

Swazey, J.P. (1992). "Those Who Forget Their History: Lessons from the Recent Past for the Human Genome Quest," in Annas and Elias, 45-56. (B)

Murray, T. H. (1992). "Speaking Unsmooth Things About the Human Genome Project," in Annas and Elias, 246-254. (B)

Paul, D.B. (1994). "Is Human Genetics Disguised Eugenics?" in Weir, 67-83. (B)

Kavka, G.S. (1994). "Upside Risks: Social Consequences of Beneficial Biotechnology," in Carl Cranor (Ed.). Are Genes Us? The Social Consequences of the New Genetics. New Brunswick, NJ: Rutgers University Press, 155-179. (R)

Weir, R. (1994.) "Why Fund ELSI Projects?" in Weir, 189-194. (B)

Lappe, M. (1985, August-September). "Biotechnology's Debt to Public Health," Technology Review, 14-15. (R)

Cook-Deegan, R.M. (1991). "The Human Genome Project: The Formation of Federal Policies in the United States, 1986-1990," in Biomedical Politics, K.E. Hanna, Ed. Washington, DC: National Academy Press, 99-168. (R)