

**Anthropological Perspectives on Genetics, Genetic Testing and Genetic Knowledge**  
 (AntM265/Psy M283) **Spring, 2001 Wed 9-11:50**  
**Professors C. H. Browner and Jill Shapira** **314 Haines Hall**  
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## **Course Description**

This class will offer a broad overview of concepts that are orienting research, clinical practice and public health programs and debates in the fields of genetics and genetic testing. Most of the work we will discuss concerns the U. S. experience.

Each day much is made in the press and other mainstream media about the “cutting edge” nature of this field. The focus is typically on the vast possibilities that genetic research holds for transforming our most basic understandings as to what it is to be human, the nature of disease and disability, the practice of medicine and law, the field of education – in essence society at its very core – and the complicated bioethical issues that accompany these developments.

This seminar will explore how sociocultural and political dynamics shape our understandings of genetic discoveries, and reciprocally, how genetic information is used to create conceptions of the self and society.

## **Requirements**

### **1. Required text:**

Wexler, Alice

1995 Mapping Fate: A Memoir of Family, Risk, and Genetic Illness. Berkeley: University of California Press.

### **Recommended texts:**

Andrews, Lori B.

2001 Future Perfect: Confronting Decisions About Genetics. New York: Columbia.

Lupton, Deborah

1991 Risk. London: Routledge.

Rapp, Rayna

1999 Testing Women, Testing Fetuses: The Social Impact of Amniocentesis in America. New York: Routledge.

The books are on reserve at the Research Library and may be purchased from the Health Sciences Bookstore, 13-126 CHS (tel 825-7721). Additional readings have been compiled into a reading packet available at Course Reader Material, 1137 /1141 Westwood Blvd., 1\_ blocks north of Wilshire next to Rite-Aid, (tel.310/443-3303). Store hours Mon-Fri 9a.m.-6p.m., Sat 10a.m.-4p.m.

2. Class sessions will consist of a group discussion based on a book, book chapters, or articles. You are required to attend each class having read the assigned readings and being ready to discuss them. **Please also come to class with a one to two paragraph abstract of each selection.** Although individual abstracts will not be graded, they are to be handed in at the end of each class and will count toward your final grade.

Each abstract should be a succinct statement of the content of the reading, the questions it raised for you, and issues you would like discussed; you may comment critically on the reading if you wish. You may want to include in the abstract your thoughts on how the reading relates to research you've done, other interests you have, or other readings for the course. The length of each abstract will undoubtedly vary according to how engaging you found the selection.

Please also rate each reading on a scale of A - F on two criteria: how much you learned from the selection; how much you enjoyed reading it.

3. You are also required to prepare a paper of approximately 20 pages on a topic derived from the broad issues that orient the seminar. The paper may be based on field research, bibliographic work, or both. We prefer that the paper to be part of one of your ongoing research interests, if possible. Your paper should be typed, double spaced, and *have left and right margins no less than 1"*. It should be proofread and corrected prior to submission. Use the style of the *American Anthropologist* or the *Medical Anthropology Quarterly* for footnotes and references. You will be required to present a brief synopsis of your research project during one of the last two weeks of class.

Please submit a one-paragraph description of your paper topic by **April 17**. Papers are due in class **June 5**. We would be happy to review and comment upon your paper=s first draft. If you have it to us by May 23, we will return it by May 30.

4. Grading

Abstracts and class discussion	50%
Term paper	50%

**We will give an Incomplete (I) only under truly exceptional circumstances. Late papers will be downgraded.**

## Syllabus

**April 3**      **Introduction: overview of basic concepts, issues, orientations, assumptions. Discussion of course requirements and instructors' and students' expectations.**

**April 10**      **Perspectives on Science, Technology and Medicine**

Jacob, Francois

1998    *Of Flies, Mice, and Men*, Chs. 6,7& Concl. Cambridge: Harvard University Press.

Fox, Renee

1977    *The Medicalization and Demedicalization of American Society*. *Daedalus* 106: 9-22.

Martin, Emily

1998    *Anthropology and the Cultural Study of Science: From Citadels to String Figures*. *Science, Technology, and Human Values* 23:24-45.

Koenig, Barbara

1988    *The Technological Imperative in Medical Practice: The Social Creation of A >Routine= Treatment*. *In Biomedicine Examined*, Margaret Lock and Deborah R. Gordon, Eds., Pp. 465-496. Dordrecht: Kluwer Academic Publishers.

Andrews, Lori B.

2002    *Future Perfect: Confronting Decisions About Genetics*, Chs. 1,2,3. New York: Columbia.

## Recommended

Haraway, Donna

1990    *The Biopolitics of Postmodern Bodies*. *In Simians, Cyborgs, and Women: The Reinvention of Nature*. London: Free Association.

Martin, Paul A.

1999    *Genes As Drugs: The Social Shaping of Gene Therapy and The Reconstruction of Genetic Disease*. *Sociology of Health and Illness* 21(5):517-38.

- Reiser, Stanley Joel  
1978 *Medicine and The Reign of Technology*. Cambridge: Cambridge University Press.
- Proctor, Robert  
1991 Introduction. *In Value Free Science? Purity and Power in Modern Knowledge*. Cambridge: Harvard University Press.
- Layne, Linda  
1998 Introduction: Anthropological Approaches to Science and Technology Studies. *Science, Technology, and Human Values* 23:4-24.
- Zola, Irving Kenneth  
1972 *Medicine as an Institution of Social Control*. *Sociological Review* 20:487-504.
- Zuriff, G. E.  
1996 *Medicalizing Character*. *Public Interest* (Spring):94-99.
- Duster, Troy  
1990 *Backdoor to Eugenics*. New York: Routledge.

#### **April 17      Theoretical Approaches to the Concept of Risk**

- Lippman, Abby  
1991 *Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities*. *American Journal of Law and Medicine* 17(1-2):15-50.
- Kenen, Regina H.  
1997 *The At-Risk Health Status and Technology: A Diagnostic Invitation and The "Gift" of Knowing*. *Social Science and Medicine* 42(11):1545-53.
- Lupton, Deborah  
1999 *Risk*, Chs. 1-3. London: Routledge.

#### **Recommended**

- Gaines, Atwood D.  
1998 *Culture and Values at The Intersection of Science and Suffering: Encountering Ethics, Genetics, and Alzheimer Disease*. *In Genetic Testing for Alzheimer Disease: Ethical and Clinical Issues*, Stephen G. Post and Peter J. Whitehouse, Eds. Baltimore: The Johns Hopkins University Press, pp. 257-274.

Michie, S., V. McDonald and Therese Marteau  
 1996 Understanding Responses to Predictive Genetic Testing: A Grounded Theory Approach. *Psychology and Health* 11: 455-470.

Quaid, Kimberly A.  
 1998 Implications of Genetic Susceptibility Testing With Apolipoprotein E. *In Genetic Testing for Alzheimer Disease: Ethical and Clinical Issues*, Stephen G. Post and Peter J. Whitehouse, Eds. Baltimore: The Johns Hopkins University Press, pp. 119-139.

Williams, J. K. and D. L. Schutte  
 1997 Benefits and Burdens of Genetic Carrier Information. *Western Journal of Nursing Research* 19:71-81.

#### **April 24 Risk Concepts I: Lived Experience**

Wexler, Alice  
 1995 Mapping Fate: A Memoir of Family, Risk, and Genetic Illness. Berkeley: University of California Press.

#### **Recommended**

Cox, Susan M. and William McKellin  
 2000 "There's Thing in Our Family:" Predictive Testing and The Construction of Risk for Huntington Disease. *Sociology of Health and Illness* 21(5):622-46.

Henderson, Bethan H. and Bryan T. Maguire  
 2001 Three Lay Models of Disease Inheritance. *Social Science and Medicine* 50: 293-301.

Brorsson, A., M. Troein, E. Lindbladh, S. Selander, M. Widlund and L. Rastam  
 1995 My Family Dies From Heart Attacks. How Hypercholesterolaemic Men Refer To Their Family History. *Family Practice* 12:433-437.

Emery, J., S. Kumar and H. Smith  
 1998 Patient Understanding of Genetic Principles and Their Expectations of Genetic Services Within The NHS: A Qualitative Study. *Community Genetics* 1:78-83.

McAllister, M. F.

1998 Men in Breast Cancer Families: A Preliminary Qualitative Study of Awareness and Experience. *Journal of Medical Genetics* 35:739-744.

Michie, S. V. McDonald and T. Marteau

1996 Understanding Responses to Predictive Genetic Testing: A Grounded Theory Approach. *Psychology & Health* 11:455-470.

**May 1 Risk Concepts II: Pregnancy and Prenatal Care**

Rapp, Rayna

1999 *Testing Women, Testing Fetuses: The Social Impact of Amniocentesis in America*, Chs. 2,3. New York: Routledge.

Press, Nancy and C. H. Browner

1997 Why Women Say Yes to Prenatal Testing. *Social Science and Medicine* 45:979-989.

Markens, Susan, C. H. Browner and Nancy Press

1999 □Because of The Risks□: How U. S. Pregnant Women Account for Refusing Prenatal Screening. *Social Science and Medicine* 49:359-69.

Browner, C. H., H. Mabel Preloran and Simon J. Cox

2000 Ethnicity, Bioethics, and Prenatal Diagnosis: The Amniocentesis Decisions of Mexican-Origin Women and Their Partners. *American Journal of Public Health* 89:1658-66.

Marteau, Theresa M. and Harriet Drake

1995 Attributions for Disability: The Influence of Genetic Screening. *Social Science And Medicine* 40(8): 1127-32.

**Recommended**

Rothman, Barbara Katz

1986 *The Tentative Pregnancy, Prenatal Diagnosis and The Future of Motherhood*. New York: W. W. Norton.

Rapp, Rayna

1999 *Testing Women, Testing Fetuses: The Social Impact of Amniocentesis in America*, Chs. 4-7. New York: Routledge.

Asch, Adrienne

1999 Prenatal Diagnosis and Selective Abortion: A Challenge to Practice And Policy. *Public Health Matters* 89:1649-1657.



Yagel, S. and E. Anteby

1998 A Rational Approach to Prenatal Screening and Intervention. *Human Reproduction* 13:1126-1128.

### **May 8            Genetics in Disability and Disease**

Middleton, Anna, J. Hewison, and R. F. Mueller

2001 Attitudes of Deaf Adults toward Genetic Testing for Hereditary Deafness. *American Journal of Human Genetics* 63:1175-80.

Press, Nancy, Wylie Burke, and Sharon Durfy

1997 How Are Jewish Women Different From All Other Women? Anthropological Perspective On Genetic Susceptibility Testing for Breast Cancer. *Health Matrix: Journal of Law-Medicine* 7:135-162.

Press, Nancy, Yutaka Yasui, Susan Reynolds, Sharon J. Durfy and Wylie Burke

2001 Women's Interest in Genetic Testing for Breast Cancer Expectations. *American Journal of Medical Genetics* 99:99-110.

Prouser, Nancy

1996 Case Report: Genetic Susceptibility Testing for Breast and Ovarian Cancer: A Patient's Perspective. *Journal of Genetic Counseling* 9:153-159.

Rapp, Rayna

2002 Testing Women, Testing Fetuses: The Social Impact of Amniocentesis in America, Ch. 10. New York: Routledge.

Welch, Gilbert H. and Wylie Burke

1997 Commentary: Uncertainties in Genetic Testing for Chronic Disease. *JAMA* 280:1525-1527.

### **Recommended**

Nelkin, Dorothy and Lori Andrews

1999 DNA Identification and Surveillance Creep. *Sociology of Health & Illness* 21: 689-706.

Wagner, Teresa M. U. and Regine Ahner

1998 Debate: Prenatal Testing for Late-Onset Diseases Such As Mutations in The Breast Cancer Gene 1 (BRCA1). *Human Reproduction* 13:1125-1126.

- Eisinger, F., G. Geller, W. Burke and N. A. Holtzman  
 1999 Cultural Basis for Differences Between US and French Clinical Recommendations for Women at Increased Risk of Breast and Ovarian Cancer. *The Lancet* 353:919-920.
- Burgess, Michael M., Shelin Adam, Maurice Bloch and Michael R. Hayden  
 1997 Dilemmas of Anonymous Predictive Testing for Huntington Disease: Privacy Vs. Optimal Care. *American Journal of Medical Genetics* 71:197-201.
- Vergeer, M. M., F. Van Balen and E. Ketting  
 1998 Preimplantation Genetic Diagnosis As An Alternative to Amniocentesis And Chorionic Villus Sampling: Psychosocial and Ethical Aspects. *Patient Education and Counseling* 35:5-13.
- Singer, Eleanor, Amy D. Corning and Toni Antonucci  
 1999 Attitudes toward Genetic Testing and Fetal Diagnosis, 1990-1996. *Journal Of Health & Social Behavior* 40:429-445.

## **May 15 Discourses on Genetics and Genetic Conditions**

### **Required**

- Ettorre, Elizabeth  
 1999 Experts As 'Storytellers' in Reproductive Genetics: Exploring Key Issues. *Sociology of Health & Illness* 21:539-559.
- Henderson, Lesley and Jenny Kitzinger  
 1999 The Human Drama of Genetics: 'Hard' and 'Soft' Media Representations Of Inherited Breast Cancer. *Sociology of Health & Illness* 21:560-578.
- Hallowell, Nina  
 1999 Doing The Right Thing: Genetic Risk and Responsibility. *Sociology of Health & Illness* 21:597-621.
- Cunningham-Burley, Sarah and Anne Kerr  
 1999 Defining The 'Social': Towards An Understanding of Scientific and Medical Discourses On The Social Aspects of The New Human Genetics. *Sociology Of Health & Illness* 21:647-668.
- Shakespeare, Tom  
 1999 'Losing the Plot'? Medical and Activist Discourses of Contemporary Genetics

And Disability. *Sociology of Health & Illness* 21:669-688.

Conrad, Peter and Susan Markens

- 2001 Constructing the 'Gay Gene' in the News: Optimism and Skepticism in the US and British Press. *Health* 5:373-400.

### **Recommended**

Bernhardt, Barbara A., Barbara B. Biesecker and Carrie L. Mastromarino

- 2000 Goals, Benefits, and Outcomes of Genetic Counseling: Client and Genetic Counselor Assessment *American Journal of Medical Genetics* 94:189-197.

Richards, M. P. M.

- 1993 The New Genetics: Some Issues for Social Scientists. *Sociology of Health & Illness* 15:567-586.

Williams, Janet K. and Debra L. Schutte

- 1997 Benefits and Burdens of Genetic Carrier Identification. *Western Journal Of Nursing Research* 19:71-81.

Finkler, Kaja

- 2001 The Kin in the Gene: The Medicalization of Family and Kinship in American Society. *Current Anthropology* 42:1-48.

### **May 22 The Human Genome Project: Social, Economic and Politics Issues**

#### **Required**

Khoury, Muin K., Wylie Burke, and Elizabeth. J. Thomson, Eds.

- 2000 Chs. 1 & 26 *In Genetics and Public Health in The 21<sup>st</sup> Century*. New York: Oxford.

Collins, Frank S.

- 1998 Shattuck Lecture -- Medical and Social Consequences of The Human Genome Project. *New England Journal of Medicine* 341:28-37.

Annas, George J.

- 1999 Some Choice: Law, Medicine, and The Market. New York: Oxford. pp. 97-111, 271-272.

Greely, Henry T.

2001 Informed Consent and Other Ethical Issues in Human Population Genetics.  
Annual Review of Genetics 35:785-800.

Belkin, Lisa

1998 The Clues Are in the Blood. *New York Times Magazine*. pp. 46-54, 120-121.

Hanson, F. Allan

2001 Donor Insemination: Eugenic and Feminist Implications. *Medical Anthropology Quarterly* 15:287-311.

### **Recommended**

Coventry, Peter A. and John V. Pickstone

1999 From What and Why Did Genetics Emerge as a Medical Specialism in the 1970s in the UK? A Case-History of Research, Policy and Services in the Manchester Region of the NHS. *Social Science and Medicine* 49:1227-1238.

Caplan, A.

1993 Neutrality Is Not Morality: The Ethics of Genetic Counseling. *In Prescribing Our Future: Ethical Challenges in Genetic Counseling*. D. M. Bartels et al, Eds. New York: Aldine De Gruyter, pp. 149-165.

Annas, George and M. A. Grodin (Eds.)

1991 The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation. New York: Rutgers University Press.

Macklin, R.

1992 Privacy and Control of Genetic Information. *In Gene Mapping: Using Law and Ethics As Guides*, George J. Annas and Sherman Elias, Eds, Pp. 157-172. New York: Oxford University Press.

White, Ray and C. Thomas Caskey

1992 Genetic Predisposition and The Human Genome Project: Case Illustrations of Clinical Problems. *In Gene Mapping: Using Law and Ethics As Guides*, George J. Annas and Sherman Elias, Eds, Pp. 173-185. New York: Oxford University Press.

White, M.

1999 Making Responsible Decisions: An Interpretive Ethic for Genetic Decisionmaking. *Hastings Center Report* 29: 12-21.

Paul, D.

- 1994 Eugenic Anxieties, Social Realities, and Political Choices. *In Are Genes Us? The Social Consequences of The New Genetics*. New Brunswick, NJ: Rutgers University Press, Pp. 142-154.

Geller, Lisa N., Joseph S. Alper, Paul R. Billings, Carole I. Barash, Jonathan Beckwith, and Marvin R. Natowicz

- 1996 Individual, Family, and Societal Dimensions of Genetic Discrimination: A Case Study Analysis. *Science and Engineering Ethics* 2:71-88.

Hubbard, Ruth and R. C. Lewontin

- 1996 Pitfalls of Genetic Testing. *New England Journal of Medicine* 334: 1192-1194.

Weijer, C. and E. J. Emanuel

- 2000 Ethics: Protecting Communities in Biomedical Research. *Science Magazine* 289(5482):1142-1144.

Anonymous

- n.d. Universal Declaration On The Human Genome and Human Rights.  
World Medical Association Recommendations Guiding Physicians in Biomedical Research Involving Human Subjects.  
Model Ethical Protocol for Collecting DNA Samples. pp. 92-130. Unpublished.

Weijer, Charles, Gary Goldsand and Ezekiel J. Emanuel

- 1999 Commentary: Protecting Communities in Research: Current Guidelines and Limits of Extrapolation. *Nature Genetics* 23:275-280.

Reilly, Philip

- 1999 Efforts to Regulate The Collection and Use of Genetic Information. *Pathology and Laboratory Medicine* 123:1066-1070.

**May 29            Student presentations**

**June 5            Student presentations**