Syllabus-Human Genetics, Ethics, and Public Policy

This course will meet for 3 hours of lecture and 1 hour of discussion per week.

Week 1
8/31-Wed-Introduction to Genetics, Cell Structure
9/2-Fri-Introduction to Bioethics

Week 2
9/5-Mon-Labor Day
9/7-Wed-Chromosomes, Mitosis/Meiosis, Human Reproduction
9/9-Fri-Infertility, Artificial Reproductive Options (In Vitro Fertilization), Cloning Human Embryos
Optional Video-"The Miracle of Life"

Week 3
9/12-Mon-Mendelian Genetics
Discussion-Regulation of Human Cloning
9/14-Wed-X-linked Diseases, Karyotyping, Amniocentesis
9/16-Fri-Sex Selection, Aneuploidies (Down's Syndrome)
Optional Video-"High Tech Babies"

Week 4
9/19-Mon-History of the Eugenics Movement-Galton, Davenport
Discussion-"Tentative Pregnancy" (Barbara Katz Rothman)-Choices following a prenatal diagnosis of Down's Syndrome, Sex selection
9/21-Wed-Eugenics, cont.-Goddard/Forced Sterilization
9/23-Fri-Eugenics in the Third Reich
Optional Video-"Gentlemen's Agreement" (1957)

Week 5
9/26-Mon-Movie-"Tomorrow's Children" (1934)
Discussion-Forced Sterilization vs. Paid Sterilization/Norplant
9/28-Wed-Positive Eugenics-Muller, Shockley, Sperm Banks
9/30-Fri-Mutation, Garrod's Inborn Errors of Metabolism-Phenylketonuria (PKU), Tay Sachs
Optional Video-"Perfect Babies"
10/1-SATURDAY-Presidential Symposium on the Ethical, Legal, and Social Implications of the "New Human Genetics"

Week 6
10/3-Mon-Molecular Biology of the Gene-DNA as Hereditary Material, Structure and Replication of DNA
Discussion-Obligations of Pregnant Women Towards Fetus (PKU)
10/5-Wed-Recombinant DNA, Asilomar Conference/Regulation of Recombinant DNA Technology
10/7-Fri-"Secret of Life" Video on Recombinant DNA

Week 7
10/10-Mon-Fall Break
10/12-Wed-Genetic Linkage, RFLP Markers
10/14-Fri-Application of RFLP's to Forensics

**Week 8**
10/17-Mon-DNA Sequencing, PCR, Application of PCR to Human Population Genetics
**Discussion**-Human Growth Hormone for Short Children
10/19-Wed-Human Genome Project-Goals, Arguments Pro and Con
10/21-Fri-Legal Aspects of the Human Genome Project-Patenting Life

**Week 9**
10/24-Mon-Mapping the Huntington's Gene
Video-"Confronting the Killer Gene"
10/26-Wed-Genetic Counseling
  Guest Lecturer: Barbara Bowles Biesecker (National Center for Human Genome Research, NIH)
10/28-Fri-Genetic Counseling of Huntington's Families

**Week 10**
10/31-Mon-Sickle Cell Anemia-The First "Molecular Disease", Population Screening
**Discussion**-Genetics as a Tool for Racial Discrimination
11/2-Wed-Cystic Fibrosis-Cloning the Gene, Population Screening
11/4-Fri-Population and Prenatal Screening-Insurance, Obligation to Fetus

**Week 11**
11/7-Mon-Genetic Screening-Cost-Benefit Analysis, Privacy
**Discussion**-Genetic Screening-Issues of Unequal Access, Perceptions of Disability, Increased Reproductive Choice?
11/9-Wed-Video-Pre-Implantation Screening of Embryos ("Making Perfect Babies"-CBC)
11/11-Fri-Genetics and Intelligence, Fragile X Syndrome

**Week 12**
11/14-Mon-Video and **Discussion**-Fragile X Screening Program (BBC)
11/16- Wed-Behavioral Traits-Homosexuality, Manic-Depression, Schizophrenia
11/18-Fri-Criminality/Violence, XYY Genotype

**Week 13**
11/21-Mon-Genetic Determinism-Alcoholism
**Discussion**-"Blood of the Fathers" (G. Frank Lydston)
11/23-Wed-Gene Therapy
11/25-Fri-Thanksgiving

**Week 14**
11/28-Mon-"Secret of Life" Video on Gene Therapy
**Discussion**-Perfectibility of Humans-Science Fiction (?) Scenarios
11/30-Wed-Gene Therapy, cont.
12/2-Fri-Cancer

**Week 15**
12/5-Mon-"Secret of Life" Video on Cancer
**Discussion**-Changing Definition of Disease-Genetic Predisposition
12/7-Wed-Cancer, cont.
Reading List—Human Genetics, Ethics, and Public Policy

The texts for this course are: Human Genetics, by Ricki Lewis (1993)
The Code of Codes, Daniel Kevles and Leroy Hood, ed. (1992)
In addition, you will be expected to purchase a photocopied anthology containing
the required readings below.
Almost all required readings are included in the photocopied anthology; the supplemental
articles and the few indicated required articles are on Reserve in Magill.

I have indicated for each day a list of required readings (including the relevant pages in
Lewis) and a list of supplemental (Supp.) readings. The supplemental articles are not
required; I have listed them in case you would like to explore a topic further or write your
research paper on this topic.

Week 1
Wed—Introduction to Genetics, Cell Structure
Lewis: 10-11, 18-20
Supp.—Suzuki and Knudtson, Genethics, pp. 94-103
Fri—Introduction to Bioethics
Reading—Kieffer, G., Bioethics: A Textbook of Issues, pp. 43-63
Wertz, D. and J. Fletcher, "Privacy and Disclosure in Medical Genetics Examined
Gert, B., "Moral Theory and the Human Genome Project", in Morality and the
HGP (Gert, ed.) (RESERVE)
Gert and Clouser, "Concerning the Inadequacies of Principalism", in Morality and
the HGP (Gert, ed.) (RESERVE)
Supp.—Overall, C., Ethics and Human Reproduction: A Feminist Analysis, pp. 1-16
Pellegrino, E., "The Metamorphosis of Medical Ethics", JAMA 269:1158-1162
(1993)

Week 2
Mon—Labor Day

Wed—Chromosomes, Mitosis/Meiosis, Human Reproduction
Lewis: 28, 34-48
Supp.—Elias and Annas, Reproductive Genetics and the Law, pp. 143-167 (History of
Legalized Abortion)
Fri—Infertility, Artificial Reproductive Options (In Vitro Fertilization),
Cloning Humans
Lewis: 342-352
Reading—Dresser, R., "Social Justice in New Reproductive Techniques", in Genetics and
the Law III (Milunsky and Annas, ed.), pp. 159-174
Robertson, "Resolving Disputes over Frozen Embryos", HCR 11-12/89, pp. 7-12
Charlesworth, Feminist Views on Reproductive Technology, in Bioethics in a
Liberal Society, pp. 88-96
Supp.—Overall, C., "Selective Termination of Pregnancy and Women's Reproductive
Autonomy", HCR 5-6/90, pp. 6-11
Fuchs, "Genetic Amniocentesis", Sci. Amer. 6/80
Grobstein, C., "External Human Fertilization", Sci. Amer. 6/79

Week 3
Mon—Mendelian Genetics
Discussion-Regulation of Human Cloning
Reading-Kolata, G., "Scientist Clones Human Embryos, And Creates an Ethical Challenge", NY Times 10/24/93

Wed-X-linked Diseases, Karyotyping, Amniocentesis
Lewis:80-86,177-182

Fri-Sex Selection, Aneuploidies (Down's Syndrome)
Lewis: 174, 182-186
Reading-Overall, C., Ethics and Human Reproduction, pp.17-39 (Chapt. 2)
Wertz and Fletcher, "Sex Selection Through Prenatal Diagnosis: A Feminist Critique", in Feminist Perspectives in Medical Ethics, pp. 240-253
Schwartz Cowan, R., "Genetic Technology and Reproductive Choice: An Ethics for Autonomy", in Code of Codes, pp. 244-265
Rothman, B. K., Tentative Pregnancy, pp. 116-154 (Chapt. 5)
Fletcher, J., "Is Sex Selection Ethical?" in Research Ethics (Berg and Tranoy, ed.), pp. 333-348
Wertz, D. and Fletcher, J., "Fatal Knowledge? Prenatal Diagnosis and Sex Selection", HCR 5-6/90, pp. 21-27
Fletcher, Kazazian, Lenzer, Childress, and Steinfels, "Prenatal Diagnosis for Sex Choice", HCR 2/80, pp. 15-20

Supp.-Warren, Gendercide

Week 4
Mon-History of the Eugenics Movement-Galton, Davenport
Reading-Ludmerer, K., Genetics and American Society, pp. 7-43
Eugenics: Twelve University Lectures, excerpts
Galton, F., Essays in Eugenics, pp. 35-39
Davenport, C., Heredity in Relation to Eugenics, pp. 67-69, 85-91
Allen, G., "Genetics, Eugenics, and Class Struggle", Genetics 79:29-45 (1975)
Supp.-Haller, Eugenics, pp. 144-159
Davenport, C., "Comparative Social Traits of Various Races", School and Society 24:344-348 (1921)
Castle, W., Genetics and Eugenics, pp. 388-405

Discussion-"Tentative Pregnancy" (Barbara Katz Rothman)-Choices following a prenatal diagnosis of Down's Syndrome
Reading-Rothman, B.K., Tentative Pregnancy, pp. 86-115, 177-216

Wed-Eugenics, cont.-Goddard/Forced Sterilization
Reading- Gould, S.J., Mismeasure of Man, pp. 158-174

**Fri-Eugenics in the Third Reich**
Reading-Kevles, D., *In the Name of Eugenics*, pp. 116-118
Supp.-Proctor, R., *Racial Hygiene*, pp. 177-222

**Week 5**

**Mon**—Movie-"Tomorrow's Children" (1934)

**Discussion-Forced Sterilization vs. Paid Sterilization/Norplant**
Reading-Columbia Journalism Review, "Seeing the Light...Or Feeling the Heat?", 3-4/91, pp. 53-57
Rees, "Shot in the Arm", New Republic, 12/9/91, pp. 16-17
Kantrowitz and Wingert, "The Norplant Debate", Newsweek 2/15/93, pp. 37-41

**Wed—Positive Eugenics—Muller, Shockley, Sperm Banks**
Reading-Muller, H.J., *Out of the Night*, pp. 78-83
Chase, A., *Legacy of Malthus*, pp. 480-488

Supp.-Muller, H.J., "What Genetic Course Will Man Steer?", Proc. 3rd Internat'l. Congress on Human Genetics (Crow and Neel, ed.)

**Fri—Mutation, Garrod's Inborn Errors of Metabolism—Phenylketonuria (PKU), Tay Sachs**
Lewis: 4-6
Goodman and Goodman, "The Overselling of Genetic Anxiety", HCR 10/82, pp. 20-27

Merz, "Matchmaking Scheme Solves Tay-Sachs Problem", JAMA 258:2636-2637 (1987)

**Week 6**

**Mon—Molecular Biology of the Gene-DNA as Hereditary Material, Structure and Replication of DNA**
Lewis: 114-126

**Discussion—Obligations of Pregnant Women Towards Fetus (PKU)**
Reading-Reilly, P. *Genetics, Law, and Social Policy*, pp. 43-61

**Wed—Recombinant DNA, Asilomar Conference/Regulation of Recombinant DNA Technology**
Lewis: 280-285
Reading- Wade N., *The Ultimate Experiment*, pp. 41-53
Supp.-Dutton and Pfund, "Genetic Engineering: Science and Social Responsibility", in *Worse Than the Disease*, pp. 174-225

**Fri—"Secret of Life" Video on Recombinant DNA**
Week 7

Mon-Fall Break

Wed-Genetic Linkage, RFLP Markers
Lewis: 76-80, 322-325

Fri-Application of RFLP’s to Forensics
Lewis: 200-204
Annas, G., "DNA Fingerprinting in the Twilight Zone", HCR 3-4/90, pp. 35-37
Supp.-Neufeld and Colman, "When Science Takes the Witness Stand", Sci. Amer. 5/90, pp. 46-53

Week 8

Mon-DNA Sequencing, PCR, Application of PCR to Human Population Genetics
Lewis: 127-130
Supp.-Cavalli-Sforza, "Genes, Peoples and Languages", Sci. Amer. 11/91, pp. 104-110
Mullis, K., "The Unusual Origin of the Polymerase Chain Reaction", Sci. Amer. 4/90, pp. 56-65

Wed-Human Genome Project-Goals, Arguments Pro and Con
Lewis: 328-336
Council for Responsible Genetics, Position Paper
Annas and Elias, "Major Social Policy Issues Raised by the HGP", in Gene Mapping, pp. 3-17
Swazey, J., "Those Who Forget Their History: Lessons From the Recent Past for the Human Genome Quest", in Gene Mapping, pp. 45-56
Watson, J., "A Personal View of the Project", in Code of Codes, pp. 164-176
Congressional Testimony, Excerpts
Kevles, D., "Out of Eugenics: The Historical Politics of the Human Genome", in Code of Codes, pp. 3-36
Watson and Cook-Degan, "HGP and International Health", JAMA 263: 3322-3324 (1990)
Erickson, D., "Hacking the Genome", Sci. Amer. 4/92, pp. 128-137
ELSI Program Activities Report (NIH), 1993

Fri-Legal Aspects of the Human Genome Project-Patenting Life
Eisenberg, R., "Patent Rights in the HGP", in Gene Mapping, pp. 226-245

Week 9
Mon-Mapping the Huntington's Gene
Lewis: 326-328
Reading-Huntington, G., "On Chorea", in Hastings Center Report 6/84, p. 6
Guthrie, W., "Chorea and Me", in Hastings Center Report 6/84, p. 7
Quaid, "A Few Words From a Wise Woman", in Genes and Human Self-Knowledge, pp. 7-11
Wexler, N., "Clairvoyance and Caution: Repercussions from the HGP", in Code of Codes, pp. 211-243
Supp.-Genome, Chapt. 1

Wed-Genetic Counseling
Bosk, All God's Mistakes, pp. 48-56
Thomson, "Communicating Complex Genetic Information", in Genes and Human Self-Knowledge, pp. 172-177
Nance, "Parables", in Prescribing our Future, pp. 89-94
Supp.-Caplan, "Neutrality Is Not Morality", in Prescribing Our Future, pp. 149-165
Rapp, R., "Chromosomes and Communication: The Discourse of Genetic Counseling", in New Approaches to Human Reproduction, pp. 25-41
Singer, "Clarifying the Duties and Goals of Genetic Counselors: Implications for Nondirectiveness", in Morality and the HGP (Gert, ed.)
Fine, "The Evolution of Non-Directiveness in Genetic Counseling and Implications of the HGP", in Prescribing Our Future, pp. 101-118

Fri-Genetic Counseling of Huntington's Families
LeRoy, "When Theory Meets Practice", in Prescribing Our Future, pp. 50-52
Gert, B., "Applying Morality to the Nine Huntington Disease Cases: An Alternative Model for Genetic Counseling", in Morality and the HGP (Gert, ed.) (RESERVE)

Week 10
Mon-Sickle Cell Anemia-The First "Molecular Disease", Population Screening
Lewis: 154-155,214
Reading-Editor, "Sickle Cell Anemia: A Race Specific Disease", JAMA 133:33-34 (1947)

Discussion-Genetics as a Tool for Racial Discrimination
Reading-King, P., "The Past As Prologue: Race, Class and Gene Discrimination", in Gene Mapping, pp. 94-114
Supp.-Hubbard, R., "Constructs of Genetic Difference: Race and Sex", in Genes and Human Self-Knowledge, pp. 195-206

Wed-Cystic Fibrosis-Cloning the Gene, Population Screening
Lewis: 16-17, 214-215, 217-218, 353
Fanos and Johnson, "Still Living with Cystic Fibrosis: The Well Sibling Revisited", 1992 CF Conf. 228-229

Fri-Population and Prenatal Screening-Insurance, Obligation to Fetus
Fletcher, J., "Knowledge, Risk, and the Right to Reproduce", in Genetics and the Law III, pp. 131-135
Supp.-Genome, pp. 285-306
Daniels, "The Genome Project, Individual Differences, and Just Health Care", in Justice and the Human Genome Project (Murphy and Lappe, ed.), pp. 110-132
Blank, R., Political Implications of Human Genetic Technology, pp. 79-124
Elias and Annas, Reproductive Genetics and the Law, pp. 109-120 (Wrongful Birth/Wrongful Life Suits)
Faden, "Reproductive Genetic Testing and the Ethics of Parenting", in Reproductive Genetic Testing: Impact on Women, pp. 142-147
ELSI Task Force on Genetic Information and Insurance, Report (1993)
Kass, N., "Insurance for the Insurers", HCR 11-12/92, pp. 6-11
Murray, T., "Genetics and the Moral Mission of Health Insurance", HCR 11-12/92, pp. 12-17
Shaw, M., "Should Child Abuse Laws Be Extended to Include Fetal Abuse?", in Genetics and the Law III, pp. 309-315
Week 11

Mon-Genetic Screening-Privacy, Employment, Cost-Benefit Analysis
Reading-Holtzman, N., *Proceed with Caution*, pp. 183-231
  Nelkin, "Social Power of Genetic Information", in *Code of Codes*, pp. 177-190
  Clarke, A., "Genetics, Ethics, and Audit", Lancet 335:1145-1147 (1990) (RESERVE)

Discussion-Genetic Screening-Perceptions of Disability, Issues of Unequal Access, Increased Reproductive Choice?
NOTE: For this particular discussion session, you may want to decide among yourselves to divide up the reading, since there is quite a lot to read.

Wed- Video-Pre-Implantation Screening of Embryos ("Making Perfect Babies"-CBC)
Reading-Bonnicksen, "Genetic Diagnosis of Human Embryos", HCR 7-8/92, pp. S5-S10
  Rothman, B.K., "Not All That Glitters Is Gold", HCR 7-8/92, pp. S11-S14

Fri-Genetics and Intelligence, Fragile X Syndrome
Lewis: 104, 156-157
Reading-Allen, G., "Genetics, Eugenics and Class Struggle", Genet. 79:29-45 (1975)
Edson, "Jensenism: The Theory That I.Q. Is Largely Determined By the Genes", NY Times Magazine 8/31/69
Kevles, In the Name of Eugenics, pp. 269-275

Week 12
Mon-Behavioral Traits-Homosexuality, Manic-Depression, Schizophrenia/Role of the Media
Lewis: 94-101, 104-105
LeVay and Hamer, "Evidence for a Biological Influence in Male Homosexuality", Sci. Amer. 5/94, pp. 44-49
Byne, "The Biological Evidence Challenged", Sci. Amer. 5/94, pp. 50-55
Kuhse and Singer, "From the Editors", Bioethics 7:3-7 (1993) (RESERVE)
Lewontin, R., Not in Our Genes, pp. 206-231
Horgan, "Eugenics Revisited", Sci. Amer. 6/93, pp. 123-131
Alliance of Genetic Support Groups, "Media Reporting in the Genetic Age: Points to Consider"

Supp.-Genome, pp. 225-248
Murphy, "Reproductive Controls and Sexual Destiny", Bioethics 4:119-142 (1990)
Thompson, "Communicating Genetics: Journalists' Role in Helping the Public Understand Genetics", in Genes and Human Self-Knowledge, pp. 104-121

Fri-Criminality/Violence, XYY Genotype
Reading-Reilly, P., Genetics, Law, and Social Policy, pp. 238-248
International Committee Against Racism, Position Paper 2/93
Allan, G., "Modern Biological Determinism: The Violence Initiative, The HGP and the New Eugenics", SOS Yearbook
Suzuki and Knudtson, Genethics, pp. 141-159

Week 13
Mon-Genetic Determinism-Alcoholism
Lewis: 105-106
Reading-Proctor, R., "Genomics and Eugenics: How Fair Is the Comparison?", in Gene Mapping, pp. 57-93
Fox Keller, E., "Nature, Nurture and the HGP", in Code of Codes, pp. 281-299
Lewontin, Biology as Ideology, pp. 21-37
Genome, pp. 249-266
Lewontin, "The Dream of the Human Genome", in Biology As Ideology, pp. 61-83
Shuster, E., "Determinism and Reductionism: A Greater Threat Because of the HGP?" in Gene Mapping, pp. 115-127

Discussion-Lydston, G.F., Blood of the Fathers
Wed-Gene Therapy
Lewis: 294-304
French Anderson, "Genetics and Human Malleability", HCR 1-2/90, pp. 21-24

Fri- Thanksgiving
Week 14

Mon-"Secret of Life" Video on Gene Therapy
Discussion-Perfectionability of Humans-Science Fiction (?) Scenarios
  Huxley, A., Brave New World, Chapt. 1, pp. 1-17
  Heinlein, R., Beyond This Horizon, Chapt. 1, pp. 1-47
  Yount, R., "Pursuit of Excellence", in Clarion Awards, 1984 (Knight, ed.), pp. 155-175
  Geisel, T., "Sneetches" (RESERVE)
Supp.-Rothschild, J., "Engineering Birth: Toward the Perfectibility of Man?",
  Lindee and Nelkin, "Genetic Futurism", in The Gene in Popular Culture

Wed-Gene Therapy, cont.

Fri-Cancer
Lewis: 264-266, 269-273
Supp.-Genome, pp. 132-178
  Weinberg, R., "Finding the Anti-Oncogene", Sci. Amer. 9/88, pp. 44-51

Week 15

Mon-"Secret of Life" Video on Cancer
Reading-Borges, Jorge, "The Lottery in Babylon", in Labyrinths, pp. 30-35
Discussion-Changing Definition of Disease-Genetic Predisposition
Reading-Caplan, A., "If Gene Therapy Is the Cure, What Is the Disease?", in Gene Mapping, pp. 128-141
Supp.-Gert, "Concept of Genetic Malady", in Morality and the HGP
  Gert, "Morally Relevant Features of Genetic Maladies and Genetic Testing", in Morality and the HGP

Wed-Cancer, cont.
Lewis: 267-269

In Addition to the Supplemental Reading listed above, the following books are also on Reserve in Magill:

General
Annas and Elias (ed.), Gene Mapping
Suzuki and Knudtson, Genethics
Gert (ed.), Morality and the Human Genome Project
Elias and Annas, Reproductive Genetics and the Law
AAAS, The Genetic Frontier
Milunsky and Annas (ed.), Genetics and the Law III
Bishop and Waldholz, Genome
Blank, R., Political Implications of Human Genetic Technology
Holtzman, N., *Proceed with Caution*
Reilly, P., *Genetics, Law, and Social Policy*
Birch and Abrecht, *Genetics and the Quality of Life*
Murphy and Lappe (ed.), *Justice and the Human Genome Project*
Miringoff, *The Social Costs of Genetic Welfare*
Duster, *Backdoor to Eugenics*
Frankel and Teich (ed.), *The Genetic Frontier: Ethics, Law, and Policy*

**Bioethics**
Kieffer, *Bioethics: A Textbook of Issues*
Beauchamp and Childress, *Principles of Biomedical Ethics*
Beauchamp and Walters, *Contemporary Issues in Bioethics*
Humber and Almeder (ed.), *Biomedical Ethics Reviews, 1991*
Charlesworth, *Bioethics in a Liberal Society*

**Reproductive Technology/Prenatal Screening (including Feminist Approaches)**
Overall, C., *Ethics and Human Reproduction: A Feminist Analysis*
Thomson and Rothenberg (ed.), *Reproductive Genetic Testing: Impact upon Women*
Corea, G., *The Mother Machine*
Spallone and Steinberg, *Made to Order: The Myth of Reproductive and Genetic Progress*
Rothman, B. K., *Tentative Pregnancy*
Berg and Tranoy (ed.), *Research Ethics*
Holmes, et al, (ed.), *Custom-Made Child*
Rowland, *Living Laboratories*
Baruch, et al. (ed.), *Embryos, Ethics, and Women's Rights*
Rapp, R., *New Approaches to Human Reproduction*
Ratcliffe (ed.), *Healing Technology: Feminist Perspectives*
Arditti (ed.), *Test Tube Women*
Overall (ed.), *Future of Human Reproduction*
Gordon, *Woman's Body, Woman's Right*
Holmes and Purdy (ed.), *Feminist Perspectives in Medical Ethics*
Cohen and Taub (ed.), *Reproductive Laws for the 1990's*
Sherwin, *No Longer Patient*
Gilligan, *In a Different Voice*
Etzioni, *Genetic Fix*
Rosenberg, *No Other Gods* (Chapt. 2)
Ramsey, *Fabricated Man*

**Eugenics**
East, *Mankind at the Crossroads*
Galton, *Hereditary Genius*
*Eugenics: Twelve University Lectures*
Haller, *Eugenics*
Gould, S.J., *Mismeasure of Man*
Rafter, N., *White Trash*
Proctor, R., *Racial Hygiene*
Kevles, D., *In the Name of Eugenics*
Reilly, P., *The Surgical Solution*
Mueller-Hill, *Murderous Science*
Trombley, S., *The Right to Reproduce* (ILL)
Muller, H.J., *Out of the Night*
Chase, A., *Legacy of Malthus*
Goddard, *The Kallikak Family*
Popenoe and Johnson, *Applied Eugenics*

**Genetic Engineering**
Wade, N., *The Ultimate Experiment*
Dutton and Pfund, *Worse Than the Disease*

**Social Power of Genetic Information**
Nelkin and Tancredi, *Dangerous Diagnostics*

**Public Policy**
Institute of Medicine, *Assessing Genetic Risk*
Office of Technology Assessment, *Biomedical Ethics in U.S. Public Policy*

**Genetic Counseling**
Bartels, LeRoy, Caplan (ed.), *Prescribing Our Future*
Bosk, *All God's Mistakes: Genetic Counseling in a Pediatric Hospital*

**Forensics**
Billings (ed.), *DNA on Trial*

**PKU**
Mendelsohn, et al., *Human Aspects of Biomedical Innovation*

**Intelligence and Genetics**
Snyderman and Rothman, *The IQ Controversy*

**Human Genome Project**
Lee, *The Human Genome Project*
Cook-Deegan, *Gene Wars*

**Determinism**
Hubbard and Wald, *Exploding the Gene Myth*
Schiff and Lewontin, *Education and Class*
Lewontin, R., *Not in Our Genes*
Lewontin, *Biology as Ideology*
Weir, et al. (ed.), *Genes and Human Self-Knowledge*

**Paper Topic: War As Dysgenic/War As Eugenic**
Reading-Jordan, D.S., "Eugenics and War", 2nd Nat'l. Conf. on Race Betterment
Proctor, R., *Racial Hygiene*, pp. 28-29, 182, 189
Jordan, *The Human Harvest*

Abbreviations: HGP=Human Genome Project
HGT=Human Gene Therapy
HCR=Hastings Center Report
JAMA=J. American Medical Assoc.
NEJM=New England J. Medicine
APJH=American J. Public Health
AJHG=American J. Human Genetics
ELSI=Ethical, Legal, and Social Implications Working Group
The Grade for this course will be determined as follows:

- 5% - Homework Set on Mendelian Genetics (due Week 4)
- 10% - Short Position Paper (2-3 pages) on Sex Selection (due Week 5)
- 10% - Short Paper (2-3 pages) on Eugenics (see topics below) (due Week 7)
- 15% - Take Home Exam (covers material weeks 1-8) (due Week 10)
- 15% - Paper (5-7 pages) on Gene Therapy (due Week 15)
- 25% - Research Paper (see below) (due end of finals period)
- 10% - Journal (see below) (to be checked each Monday)
- 10% - Class Participation

Short Paper on Eugenics: You may choose one of several topics:

1) Many eugenicists took a pacifist stance, arguing that war was dysgenic. However, one could also argue that war is eugenic. Explore this topic, with reference to arguments both in the US and in Germany.

2) The Eugenics movement in the US emphasized, among other things, how many prominent men in academia came from families with a distinguished history in academia and the professions. Was this intellectual elitism or a simple observation of fact? Is there intellectual/academic elitism today, in American society as a whole or at Haverford? Why or why not?

3) Is offering women on welfare money to use birth control (e.g. Norplant) different than the forced sterilizations of the early 20th century?

4) A television reporter in Los Angeles, Bree Walker Lampley, has a dominant genetic condition that results in webbed fingers. Jane Norris, a radio talk show host in LA, made Walker Lampley's pregnancy a talk-show issue, by inviting discussion on whether it was right for Walker Lampley to get pregnant, given that each child would have a 50% chance of inheriting the condition. Is this a eugenic issue, or simply a question of someone being a busy-body? Does society have a right to discuss Walker Lampley's choices? Why or why not?

Research Paper: I would like you to write about a topic that has especially excited or interested you during the term. I have offered some suggestions below, but feel free to design a topic on your own, in consultation with me. I would like you to think particularly about the issues of prejudice, equity, and/or social justice inherent in the topic you choose. I will ask for a preliminary idea of your topic in Week 12, and a firm commitment on a topic in Week 14.

Possible topics:

1) Explore the controversy surrounding the genetic basis for intelligence.
2) Explore one or more aspects of the Eugenic movement historiographically.
3) Explore the questions of reproductive choices arising from prenatal diagnosis and screening. Do the new technologies empower women or control them?
4) Explore the ways in which prenatal screening and genetic counseling are inequitable with regard to race and social status.
5) Explore the issues of privacy and/or insurance problems associated with the new genetic technologies and knowledge.
6) In what ways did the Eugenics movement reflect and/or affect the place of women or the perception of women in early 20th-century society? Do the current advances in genetic and reproductive technologies have a similar effect? an opposite effect? (Gena Corea's book The Mother Machine will be a good place to start.)
7) Trace the evolution of societal attitudes towards the handicapped through the Eugenics movement to the present climate of prenatal testing.
8) Trace the development of the technology that led to the decrease in birth rate among the upper classes. Are the issues concerning relative birth rates that were raised during the Eugenics movement still issues today? (Chapter 2 of No Other Gods by Rosenberg and Woman's Body, Woman's Right by Gordon will be good places to start.)
9) Are we in (or approaching) a "Brave New World"?
10) Is the Human Genome Project reductionist? Is reductionism necessarily bad?
If molecular biology is reductionist, does it stem in any way from the fact that the sciences
traditionally have been male-dominated fields?
11) What are the roots of (the philosophical doctrine of) genetic determinism? In
what ways does determinism pervade our society today?
12) In what ways do media portrayals influence our perceptions of new genetic
technologies and findings? In what ways does the language used (e.g. "the gene for cystic
fibrosis", "the gay gene") influence our ideas about mutation?
13) Explore the issue of "geneticization" of disease (to use Abby Lippman's term). How
do the new genetic technologies contribute to the "construction of the healthy ill"
(Ruth Hubbard's term)? How will (or should) this influence the allocation of limited
health-care resources?
14) Explore the uses of genetic arguments to justify discrimination in today's
society. What are the underlying assumptions inherent in taking such a biological
approach? (This topic could take many forms: differential birth rates, violence, sexual
orientation, etc.) Will the knowledge gained from the Human Genome Project alleviate or
exacerbate these issues?
15) Consider the motives, rationales, and means of the Eugenics movement in the
first half of this century. Should the current (or impending) applications of genetic
technologies be considered "eugenic"?

Journal: I would like you to keep a journal as we go through this semester. This journal
should provide you with an opportunity to express your reactions to the course, and
especially to the many very sensitive issues that we will be discussing. Although I would
urge you to express your opinions in the class discussion sessions, I recognize that there
may not be time to adequately explore a topic, or you may have an opinion that you do not
feel comfortable expressing in that setting. I hope the journal will give you a chance to put
those thoughts on paper. I will be the only one who sees your journal, and the content of
your opinions will not influence your grade on this assignment, so please feel free to write
what's really on your mind. I will collect the new journal entries each Monday, so please
keep them in a loose-leaf format.

From time to time, I will offer suggestions for topics for thought, so that you will
have something to write about even if nothing else strikes you that week. For example, for
the first week, I would like you to consider the recent case of the Ayala family in
California. The family learned that their 17-year-old daughter had a fatal form of leukemia
and needed a tissue transplant, but no suitable donors could be found. The parents decided
to have another child in the hope that that child would be genetically compatible and would
be able to donate tissue. Examine this case from each of the various ethical perspectives we
have discussed. In each case, discuss whether the family's decision to have this child was
morally justifiable.

Class Participation: The class will be divided into discussion groups of ~ 10 students each.
I will rotate through the sections, so I can get a feel for the dynamics of each group and the
thoughts of the group on the topic of the week. Since class participation is 10% of your
grade, I expect you to be an active participant in your section. Each week, 2 students will
be designated as discussion leaders. From time to time, we may experiment with a role-
playing situation, where students represent one side or another of a given issue.

I strongly encourage you to use the Writing Center (896-1396) as a resource when writing
your papers for this course. The Center is located in Founders 031 and is open 8-11 pm on
Sunday to Thursday, and 2-5 pm on Sunday.