COURSE OBJECTIVES:

1. Survey the ethical and social issues related to human genetics research and clinical practice.
2. Conduct projects to develop skills necessary for multidisciplinary research.

RATIONALE:

Understanding the range of ethical issues raised by genetic testing and research requires moving beyond traditional approaches to bioethics. The social, cultural and economic contexts that shape health and health care delivery are at least as important to genetics as other areas of clinical service and research. Similarly, understanding the experiences of patients and families and the meanings they attach to genetics and to "risk" are central to a full understanding of the ethical issues raised by genetics. Research into these areas is necessarily collaborative and multidisciplinary. It is therefore important that graduate education for students planning to work in health care fields, and particularly genetics, develop an understanding of the various perspectives and methods, as well as an ability to communicate across disciplinary boundaries. This course is intended to bring together a mix of graduate students in genetics, genetics counselling, philosophy, nursing, anthropology, sociology, social work, psychology and other sciences with residents and clinical fellows in genetics. Rather than duplicate existing introductory courses to bioethics or related disciplines, the subject matter of this course will be the rapidly advancing interface between genetics, ethics, and the social sciences. Participation in seminar discussions will be facilitated by the use of case and policy examples.

COURSE FORMAT:

Weekly seminars will involve presentations and group discussions. The first two classes will introduce some key cases and policy issues in human genetic research and clinical practice. These examples will demonstrate the relevance of multidisciplinary analyses, establish the range of ethical issues to consider in genetics, and serve as examples for reference throughout the course.

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* Initially designed by Dr. Michael Burgess (Centre for Applied Ethics, UBC) in 1997, redesigned and taught by co-instructors M. Burgess and clinical geneticist Dr. Laura Arbour, this latest revision is by Dr. Fern Brunger, the instructor for 2001. The course is offered every year, and the syllabus is revised and posted every January.
The next four classes will introduce specific disciplinary perspectives, moving from micro-level to macro-level inquiries into ethics and genetics. Micro-level approaches will include sociological, feminist, and narrative or "meaning-centred" theories and methods, which will be introduced through presentations of research on experiences within families at risk for hereditary illness. Macro-level approaches will emphasise meaning in its relation to power, through presentations of research on the culture and commercialization of genetic research.

The second half of the course will emphasise participants' presentations of proposals and final reports. The final class will review the relevance of the various disciplines and their integration in multidisciplinary analysis.

Student projects will involve small group collaboration on a multidisciplinary research project. A request for proposals in two or three areas will be distributed at the first class. Two or three students will collaborate to propose projects for approval of the instructors by the fourth week. Written reports are due in the last week of term. Both written proposals and final written reports will be preceded by verbal presentations in the class. Class participants will also comment on two written proposals.

REQUEST FOR PROPOSALS

Course participants will form two or three-person research teams, preferably from different disciplines. Each group will respond to one of several "request for proposals" distributed during the first class (more than one group can work on a topic). Participants should get to know each other before committing to working together on the projects. Some time socializing following the first class will facilitate collaboration.

EVALUATION

Final grade will be based on a written proposal (10%), final paper (70%) and ability to participate in multidisciplinary collaboration (20%).

Project proposal must clearly outline a question or issues that the group will pursue, the relevance to the request for proposals, how their approach will be able to answer the question, and present enough substance for the other course participants to critique the proposal. Two-page outlines and 10-15 minute presentations are due on Feb 5 or 12. Written proposals (2-5 pages) are due on February 26 (3 copies). Evaluation of proposals will be based on the oral presentation and written presentation.

The final paper (15-30 pages) will be presented orally on the assigned day in March and the final report due at the Centre for Applied Ethics on April 2. Conciseness will be valued and breadth of perspective must be tempered with a definite focus and relevance of material. Evaluation of the final paper will be based on the oral presentation, discussion, and written paper.
**Participation** will be assessed through participation in seminars, willingness to openly articulate thoughts, ability to listen and incorporate others' comments, and two 1-2-page reviews of others' written proposals (assigned on February 26 and due March 5). Members of the same group may receive different grades based on participation and based on obvious differences in contribution to the final project.

**Policy on late written work**: No extensions are given after the deadline is past. Penalties are 5% off for 1-6 days late; 10% off for 7-14 days late. No papers are acceptable after 14 days. All written work will be typed, double-spaced, with 1-inch margins on 4 sides. Due to the tightness of the schedule, oral presentations are not open for rescheduling.

**COURSE RESOURCES**

**Required Readings.**
The following two volumes will be used throughout the course.


Other required and recommended readings are listed under topics by date, below.

**COURSE SCHEDULE AND READINGS**

**PART I. INTRODUCTION TO ETHICS AND GENETICS**

**January 8**: Introducing the course, each other, and trajectories of inquiry: clinical ethics/research ethics; micro-level/macro-level; meaning/power; Socializing afterwards to help choose colleagues for group research.

**January 15**: (Laura Arbour, Michael Burgess) Policy issues and case studies: Clinical ethics in genetics.

Required Readings: (available from instructor in advance and distributed in class):


Recommended Readings:


PART II: MICRO-LEVEL INQUIRIES: Clinical ethics & experiences around genetic testing; narratives of risk; meaning-centred approaches.

January 22: (Lori D'agincourt) 'Relational responsibility' and experiences of women at risk for hereditary breast cancer,' (Jessica Easton) (Re)creating life lines: Experiences of adolescents at risk for Huntington's disease.

Required Readings:


Recommended Readings:


- Scheduling of oral presentations of proposals

January 29: (Susan Cox) Experiences of individuals and families around susceptibility testing for Huntington's disease and Polycystic Kidney Disease; (Christine Maheu) Experiences of women with a risk status of "unknown" for breast and ovarian cancer genetic susceptibility.

Required Readings:

Recommended Readings:

PART III: MACRO-LEVEL INQUIRIES: Research ethics and the biotech industry; commercialization and the production of genomic knowledge; culture in its relation to power.

February 5: (1) Research ethics in genetics: culture and the production of genetic knowledge (Brunger); (2) (Bryn Williams-Jones) Commercialization and genetic testing.

- Oral proposal presentations (first 2-3 groups)

Required readings.

Recommended readings.

February 12:
(Paul Reynolds, School of Communication, SFU) *Maori, genes and genetics: The impact of biotechnology on indigenous peoples.*

- Oral proposal presentations (last 2-3 groups)

Required Readings:

Recommended Readings: tba

February 19: NO CLASS, BREAK

PART IV: APPLICATIONS

February 26: *Mock press releases*, in collaboration with UBC School of Journalism.

- Submission of final proposals (written)
- Assignment of others' proposals to review (2 each)

March 5: *Synthesis/Review, meaning in relation to power: Implications for clinical decision-making, research and policy.*

- Submit 2 reviews of others' proposals

March 12: *Group reports* (30-40 minute presentation) and discussion

March 19: *Group reports* (30-40 minute presentation) and discussion

March 26: *Group reports* (30-40 minute presentation) and discussion

April 2: FINAL PAPERS DUE