

**Genetics and Ethics**

INDS 502K/MEDG 535 (3)

Course instructor: Stephanie Brown, MS, CGC, CCGC

Time: Tuesdays, 4:00-6:30,

Online – Zoom platform

Office Hours: as needed

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UBC Canvas - canvas.ubc.ca

Library Site: [www.library.ubc.ca](http://www.library.ubc.ca)**Important dates**

- Classes start January 12<sup>th</sup> 2021
- Midterm reading week (no class) February 16<sup>th</sup> 2021
- Midterm paper due: February 23<sup>rd</sup> 2021
- Final paper due: April 13<sup>th</sup> 2021

**Objectives**

Upon completion of this course, participants will be able to:

1. Demonstrate a broad understanding of principle-based and other approaches to bioethics
2. Articulate the major ethical and social issues relating to clinical practice and research in medical genetics
3. Understand the applications of bioethics in clinical practice and demonstrate skills in case-based ethical analysis and decision-making
4. Demonstrate the ability to review material (scientific and lay literature) relevant to the course in a concise, yet comprehensive manner, with a clear and well supported opinion on said material.

**Approach**

This course covers ethical and social issues relating to research and clinical practice in medical genetics and genomics. It is primarily directed to graduate students in Genetics, Medical Genetics, and Genetic Counselling; residents and clinical fellows in medical genetics; as well as interested students in the IISGP Program. Students in social and natural sciences, humanities, and professional programs may participate if numbers allow – voices from other disciplines and perspectives help to enrich the dialogues and inform our discussions. The course adopts a case-based approach to assist students to develop basic skills in practical moral reasoning and bioethics. Assigned readings, genetics- and bioethics-related news stories, and in-class discussions will help participants situate questions of practice within broader social and political debates.

UBC provides resources to support student learning and to maintain healthy lifestyles but recognizes that sometimes crises arise and so there are additional resources to access including those for survivors of sexual violence. UBC values respect for the person and ideas of all members of the academic community. Harassment and discrimination are not tolerated nor is suppression of academic freedom. UBC provides appropriate

accommodation for students with disabilities and for religious observances. UBC values academic honesty and students are expected to acknowledge the ideas generated by others and to uphold the highest academic standards in all of their actions.

Details of the policies and how to access support are available on [the UBC Senate website](#).

### Readings

Course readings can be found on UBC Canvas. Course participants will read the required articles and view videos, and for each seminar be prepared to contribute to class discussion on the material.

For those who would like to read other personal stories related to patient experience and genetics, the following books may be of interest to you:

- Anne Fadiman's *The Spirit Catches You When You Fall Down*, is a story of an immigrant family that has different understandings and assumptions of diseases from the health-care providers and the mainstream population.
- Alice Wexler's *Mapping Fate: A Memoir of Family, Risk, and Genetic Research*, explores the journey of a family dealing with Huntington's disease.
- Martha Beck's *Expecting Adam*, tells the story of a young academic mother awaiting the birth of a Down syndrome baby.
- Fern Kupfer's *Before and After Zachariah*, is an account of a couple coping with the life changing journey of deciding how to care for a child with a rare degenerative brain disease carried in the recessive genes of both parents.
- Barbara Katz Rothman's *Tentative Pregnancy* explores how amniocentesis has changed the way we think about pregnancy, childbirth, and parenthood.
- Rebecca Skloot's *The Immortal Life of Henrietta Lacks*, documents the history of Henrietta Lacks and the *HeLa* cell line raising numerous ethical issues surrounding scientific advancement, research, consent and ownership.

### Assignments

1. **Course participation** includes active engagement and dialogues in the course and reading the assigned articles, as well as several in-class “for/against” debates on a variety of issues. For/Against debates should demonstrate understanding of bioethical theories/ principles, raise important questions, and allow students to develop arguments for or against certain contentious ethical issues. Students will be split into groups to argue ‘for’ or ‘against’ a certain position.
2. The **short critical case analysis\*** will be given as a take home. Grades for this will be based on improved ethical reasoning, and short paper submission (3-5 pages). Due Feb 23<sup>rd</sup>.
3. The final paper is a **critical literature review\*** (10-15 double spaced pages) for one of the areas identified in the course. Due April 13<sup>th</sup>

### Grades

Online for/against discussion/ in class debate

25%

Class participation/ literature commentary	10%
Case analyses (Feb. 23)	25%
Final critical literature review(Outline March 16 Paper Apr 13)	40%

*\*Details on the cases analyses and final critical literature review format and expectations are provided at the end of this syllabus*

***The case analysis and final critical literature review should be submitted in via assignments in Canvas or if that fails by e-mail to - sbrown@cw.bc.ca***

**COURSE SCHEDULE Readings are listed on Canvas****Class 1 (Jan 12<sup>th</sup> 2021)**

- Introduction of course and syllabus review
- Organizing critical literature reviews and case analysis
- Group assignments
- Morality, professionalism, ethics and law
- Codes of Ethics

**Class 2 (January 19<sup>h</sup> 2021)****Introduction to Ethical Theory and Principles**

1. Introduction to theories of ethics.
  - a. Virtue ethics
  - b. Deontology
  - c. Utilitarianism
  - d. Casuistry
2. The four principles.
  - a. Beneficence.
  - b. Non-maleficence.
  - c. Autonomy.
  - d. Justice

**Class 3 (January 26<sup>st</sup> 2021)– Decision Making Frameworks**

- The four box model
- Ethical Theories and Principles in Practice

**Class 4 (February 2<sup>nd</sup> 2021) – Ethical issues in treatment of genetic disorders – a focus on achondroplasia**

- Historical context
- What is treatment?
- How are patients identified?
- Costs

**Class 5 (February 9<sup>th</sup> 2021)– Ethics of ART**

- Ethical issues with ART and Fertility
  1. Privacy/anonymous donors
- Three-person IVF
- Pre-implantation genetic diagnosis

## **February 16<sup>th</sup> – Midterm Break**

### **Class 6 (February 23<sup>rd</sup>) – Ethical Issues in Prenatal Genetics and Direct to Consumer Testing**

- Prenatal Screening (close look at NIPT)
- Whose result is it
- Prenatal Exomes
- Maternal autonomy in the context of EDP/surrogacy.
- Ancestry testing

### **Class 7 – (Mar 2<sup>nd</sup>) - Ethical issues in Pediatric Care - a Provider's Perspective**

- Parental decision making process
- Quality of life
- Impact on health care providers.
- Case based review

### **Class 8– (Mar 9<sup>th</sup> ) Privacy, Genetic Discrimination and Duty to Warn**

- Discrimination
- Duty to Warn
- GINA/GNA
- Right not to Know
- Parent's versus Child's Autonomy

### **Class 9 (Mar 16<sup>th</sup>) research ethics**

- Biobanks
- Databanks
- Ethics of research privacy

### **Class 10 – (Mar 23<sup>rd</sup>) Ethical Issues in the Laboratory Setting**

- Variant re-interpretation
- Duty to Recontact
- Non-Paternity (and other biological secrets)

### **Class 11 (Mar 30<sup>th</sup>) Ethical issues in hereditary cancer genetics and tumor analysis**

- Should hereditary cancer syndromes be considered reportable
- Genetic testing in the dying/recently deceased
- Secondary findings in oncology
- Another look at research ethics

### **Class 12 (April 6<sup>th</sup>) – Ethical Issues in Clinical Research**

- Adult and pediatric testing

- Incidental Findings

**Class 123 – (Apr 13<sup>h</sup>) Case Analysis and gene editing**

- In class discussion: Gene editing
- Solving ethical dilemmas - application of the four box method
  - 3 cases – SEE CANVAS
- Review of course material
- Questions and wrap up

**For/Against Group Assignments:**

Please see assignments in Canvas for specific topics and supporting material. There are four for/against assignments in total.

You will be assigned to one of three groups for the entire semester. Topics will be presented during class in a debate format. One group will be assigned the "for" position, the other "against" and the third group will be providing a written summary of key points of each position and a decision as to the group with the most persuasive position with a reasoned explanation. This submission should be about one page and is due the following class.

The "for" and "against" groups should submit **prior to** class a summary of their position. This should be less than 3 pages including references. It can be in bullet point format.

You will be expected to work with your group to come up with a group position/argument supporting your position. It is up to you how you decide to work together, but this exercise is aimed at getting you to work together, and synthesizing multiple viewpoints, as well as encouraging your debating skills! Please note that the position you are asked to support/ argue for may not represent your individual viewpoint, but the task will hopefully allow you to explore different perspectives on controversial issues in genetics.

**Case Analysis (3-5 pages double spaced)**

**Due Date: Feb 23<sup>rd</sup>**

This assignment is an exercise on identifying and analyzing the ethical concerns that arise in a specific case or a particular issue that relates to genetics

**Case: Saviour siblings** (Molly Nash case - *please google case*)

Case analysis should include:

Summary: A synopsis of the situation – what brought the patient/family to consider using PGD to create a saviour sibling, Molly's diagnosis, available therapeutic options for Molly, life expectancy, techniques involved in creating the saviour sibling, previous cases of similar sort

Ethical issues: What is the key ethical issue in this situation? Is it ethical to use PGD to create a saviour sibling? Are there general ethical issues surrounding the use of PGD in general? Are there specific issues regarding saviour siblings?

Analysis: How does such procedure benefit or harm those involved? Would this pass the universalization test? Is the creation of PGD using embryos as mere means? Would the overall benefit outweigh the costs?

Conclusion: After analyzing the issues, were the parents justified in creating a saviour sibling for Molly? What are the reasons for such conclusion?



**Critical Literature Review** (10-15 double spaced pages)

Due Dates: March 16<sup>th</sup> (Outline); April 13<sup>th</sup> (Final Paper)

This assignment is an exercise on identifying and critically evaluate various positions/concerns in the literature regarding one of the areas identified in the course. Students may make their own choice of topic depending on their own specific interests. For example, it can be a review paper regarding testing children for late onset disease, or it can be about testing for certain traits that have been socially marginalized (e.g., the “gay” gene, or opting for embryos with the deafness genes).

Please keep in mind that there are two interconnected main goals to this assignment – it is a literature review, but a critical one. Regardless of the topic you choose, you'll need to do a literature search on ethical implications regarding this issue, keeping in mind that there are likely to be at least two positions on this issue. In some ways, this is a similar paper as the case analysis – but for this critical literature review, you'll be expected to look not only at the articles that we have covered, but also at other literature.

So, here's an example of what the review can look like, keeping in mind that this is not the only way to proceed:

**Introduction** – Briefly explain what issue it is that you are going to discuss, and why this is a significant ethical issue. For example, let's say you want to write about Deaf couples who want to use PGD to help only implant embryos that have the deafness genes. Also explain briefly the technological implications of such practice – what's involved, success rate, risks/benefits, etc.

**Ethical questions** -- Briefly explain what leads some people to want this procedure, and what the general ethical questions may be regarding such practice. What principles may be relevant in thinking about such issues? What theories are important (e.g. utilitarianism)?

**Literature review** – In reviewing the literature, please make sure to include ethical perspectives on the issue at hand. For example, what have others said about using PGD to implant embryos with the deafness genes in the literature? What have people said about why we should allow/offer such testing and PGD? What have others said about not offering/allowing such testing and PGD? Do people say something completely different in cases where people choose PGD to AVOID having a child with deafness?

**Critical review** – What do you think of these arguments put forth by others on the various sides of this issue? Are they convincing? What are the strengths and weaknesses of each of these positions? Are there elements that one or more of these positions have neglected? Are there unknown factors that we need to clarify before being able to reach a sound ethical decision regarding such practice?

Implications – Before closing, please briefly explore the implications of this issue that you're discussing (although this can also be incorporated into your review sections). For example, would allowing PGD in choosing deafness imply certain things about disability in general? Would using such procedure lead to a floodgate of prospective parents choosing other characteristics? Is the use of PGD in such a case similar to other types of parental and/or reproductive autonomy?

Conclusion – Briefly explain the lessons learned, or what future direction you think ethicists and others (e.g., the profession) should take with this issue at hand.