

Genetics and Medicine: Ethical, Legal, and Social Implications — Spring 2024

Instructor: Madison K. Kilbride

GENERAL INFORMATION

Location:

All classes will be held on Zoom.

Course numbers and credit hours:

PHIL 6191-002 (2 credit hours)

H GEN 6700-001 (2 credit hours)

LAW 7906-001 (2 credit hours)

MD ID 7251-001 (2 credit hours)

Time:

Wednesday 5:20p — 7:20p MT

Contact information:

Email: madison.kilbride@utah.edu

Zoom:

Zoom link: <https://utah.zoom.us/j/98823423384>

Passcode: ELSI2024

Course materials:

There is no assigned textbook. All reading assignments will be posted to Canvas by the Thursday before each class session. Readings will typically consist of 1-2 articles. Students are expected to read all assigned materials in advance of each class and be prepared to participate in class discussions.

Office hours:

While I will not have scheduled office hours this semester, I am happy to meet via Zoom. Please email me to arrange a time to meet.

Course description:

This graduate-level course will introduce students to the ethical, legal, and social implications (ELSI) of human genetics and genomics research. The course will meet (on Zoom) for 13, two-hour sessions throughout the Spring semester. Through lectures, class discussions, and case study analyses, students will have the opportunity to critically examine and explore current and emerging ELSI topics.

Course outcomes:

At the end of this course, students will be able to:

- (1) Describe the ethical, legal, and social implications of human genetics and genomics research.
- (2) Articulate different views and positions related to the ELSI topics covered in class.
- (3) Analyze a case study by identifying the relevant:
 - a. Ethical, legal, and social issue(s) at play
 - b. Stakeholders
 - c. Competing values
 - d. Potential resolutions

Course format:

This course will consist of didactic lectures, interactive discussions, and case-study analysis. Class sessions will be led by Professor Kilbride or by a guest speaker who is an expert on a particular topic.

Announcements:

Announcements—including changes to the classes schedule, readings, or assignments—will be posted on Canvas. Canvas notifications will be sent to whichever email address is linked to your University of Utah Canvas account. Students are responsible for checking their email regularly and reading all announcements. If you would like to contact me, please email me directly at madison.kilbride@utah.edu. Since announcements may also be made at the beginning of class, it is very important that you come to class on time.

Recordings and Slides:

Classes may be recorded; however, the recordings will not be made available or distributed to students. I will post lecture slides after each class session. Slides are intended as a supplement to—and not a substitute for—attending class.

Zoom Protocol:

- Class will begin at 5:20p sharp. It is recommended that you log into Zoom and join the class session at 5:15p—five minutes before the start of class. If you are late to class without a legitimate excuse, I will factor that into your attendance and participation grade.
- In general, I will plan to hold a five-minute break close to the midpoint of class.
- Please keep your camera on during class.
- While I recognize that background disruptions and distractions are sometimes unavoidable, please try to keep them to a minimum.
- Please keep your microphone muted when not speaking.
- Please join the class from a computer or tablet and not a smartphone or other mobile device. This will allow you to easily view the PowerPoint slides, “chat” thread, and your fellow classmates.
- If you have a question or comment, please use the “Raise My Hand” function. While I will do my best to monitor the “chat” thread, I may miss a comment or question.

- Students may use the “chat” function to communicate with the entire class, the instructor, or specific individuals. That said, please use caution and be judicious about the content you put into “chats,” including those that are “private.”
- Be respectful in your interactions with other students, guest speakers, and the instructor.

ASSIGNMENTS AND GRADING

- (1) Classroom engagement: 40%
 - a. Attendance and participation: 20%
 - b. Discussion Leadership: 20%
- (2) Final exam: 60%

(1) Classroom Engagement:

Attendance and Participation: Attendance in class is mandatory. I will be taking attendance at each class session. Students are permitted to miss two classes during the semester without a grade reduction or other penalty. Students do not need to obtain prior approval from the instructor to miss two classes. For each additional class session that is missed, your grade for the course will be reduced by one-third of a letter grade. If more than four class sessions are missed during the semester (absent written approval from your Dean of Students or another program director), you cannot receive credit for completing the course. If you have a significant extenuating circumstance that impacts your attendance, please reach out to me, and we can discuss the matter further. Your attendance and participation grade will be updated in Canvas at the mid-semester point.

Discussion Leadership: Throughout the semester, each student will serve as a Discussion Leader twice—once for a class that I teach and once for a class that is taught by a guest lecturer.

As a Discussion Leader, please come to class with a set of prepared questions based on the readings to help foster an active and engaging class discussion. Additionally, please be ready to share your thoughts and responses to the lecture and the evolving class discourse.

After the first class, you will be asked to sign up to be a Discussion Leader for two separate classes. You will be graded on the quality of your contributions to the class discussion. **Leading two discussions will count for 20% of your grade**—10% for each class you lead. Please do not miss the days for which you are signed up to be a Discussion Leader. If, however, you must miss class due to an illness or other extraordinary situation, please reach out to me as soon as possible so that I can approve the absence and alternative arrangements can be made.

While Discussion Leaders are required to participate in the class discussions they are leading, all students are encouraged to participate in each class session.

(2) Final Exam

The final exam will comprise 60% of your grade. The final exam will be available on Monday, April 15th by 5p MT and will be due on Monday, April 22nd by 5:00p MT. Late submissions will not be accepted. In the event of an illness or other extraordinary situation, a letter from your Dean of Students or another program director will be required.

The final exam must be submitted as a Microsoft Word document through Canvas. Please include your full name, the name of the class ("Genetics and Medicine: ELSI"), and the date you submitted the assignment in the upper righthand corner of the document.

The final exam will consist of a set of questions based on a case study. For the exam, you will be asked to identify, explicate, and analyze the ethical, legal, and social issues raised by the case, drawing on concepts covered in class. Additional information will be provided as we get closer to the exam period.

CLASS SCHEDULE*

Class	Date	Topic	Instructor
1	Jan. 10 th	Introductions, intro to ELSI	Kilbride
2	Jan. 17 th	Overview of genetic testing	Kilbride
3	Jan. 24 th	Genetics and the family	Kilbride
4	Jan. 31 st	Whole genome sequencing and the NICU	Carrie Torr
5	Feb. 7 th	Direct-to-consumer genetic testing	Kilbride
6	Feb. 14 th	Patents and genetic material	Jorge Contreras
7	Feb. 21 st	Genetics and research ethics	Kilbride

8	Feb. 28 th	Challenges to equity and access with precision medicine	Jim Tabery
-----	Mar. 6 th	NO CLASS	-----
9	Mar. 13 th	Genomic medicine, diagnosis, and treatment	Joshua Bonkowsky
10	Mar. 20 st	Genetics and pediatrics	Kilbride
11	Mar. 27 th	TBD: Genetics and the law (GINA and ADA) or disability and human rights	Leslie Francis
12	Apr. 3 rd	Boilerplate contracts and genetic testing	Jason Iuliano
13	Apr. 10 th	Genetics and reproductive ethics	Kilbride
14**	Apr. 17 th	Make-up class (if needed)	TBD

*Topics and speakers may be rearranged or altered if necessary

**Class may be held this date to make up for a cancelled session

ACADEMIC CODE OF CONDUCT

University of Utah regulations pertaining to the academic code of conduct apply to all written assignments for this class. These regulations are stipulated in The Student Code for the University of Utah. This document can be found at: <https://regulations.utah.edu/academics/6-400.php>

REQUIRED STATEMENTS FOR THE UNIVERSITY of UTAH

The Americans with Disabilities Act:

The University of Utah seeks to provide equal access to its programs, services, and activities for people with disabilities. If you will need accommodations in this class, reasonable prior notice needs to be given to the Center for Disability & Access, 162 Olpin Union Building, (801) 581-5020. CDS will work with you and the instructor to make arrangements for accommodations. All written information in this course can be made available in an alternative format with prior notification to the Center for Disability & Access

Addressing Sexual Misconduct:

Title IX makes it clear that violence and harassment based on sex and gender (which includes sexual orientation and gender identity/expression) is a civil rights offense subject to the same kinds of accountability and the same kinds of support applied to offenses against other protected categories such as race, national origin, color, religion, age, status as a person with a disability, veteran's status or genetic information. If you or someone you know has been harassed or assaulted, you are encouraged to report it to the Title IX Coordinator for the College of Law, Dean Brian Burton, or the Title IX Coordinator in the Office of Equal Opportunity and Affirmative Action, 135 Park Building, 801-581-8365, or the Office of the Dean of Students, 270 Union Building, 801-581-7066. For support and confidential consultation, contact the Center for Student Wellness, 426 SSB, 801-581-7776. To report to the police, contact the Department of Public Safety, 801-585-2677(COPS).

University Safety Statement:

The University of Utah values the safety of all campus community members. To report suspicious activity or to request a courtesy escort, call campus police at 801-585-COPS (801-585-2677). You will receive important emergency alerts and safety messages regarding campus safety via text message. For more information regarding safety and to view available training resources, including helpful videos, visit safeu.utah.edu.