

MD ID 7252 / LAW 7906 / HGEN 6700 Genetics and Medicine: Ethical, Legal and Social Issues Spring 2021, 2 credits Wednesdays 5-7pm (Zoom)

Instructor: Prof. Jorge L. Contreras Email: jorge.contreras@law.utah.edu Co-Instructor: Dr. Amy J. Hawkins Email: amy.j.hawkins@utah.edu

Reading Materials

There is no assigned textbook. Reading assignments will be made available on Canvas at least one week before each class session.

Course Description

This course is designed to immerse students in the emerging ethical, legal, and social issues facing the use and practice of genetics in medicine. This is a semester-long, weekly course that meets for 12, two-hour online sessions. The course offers a mix of didactic content, case studies, and class discussion. This course is intended for students with graduate standing and is targeted toward students who have at least some basic knowledge of human genetics.

Course Outcomes

At the successful completion of this course, students will be expected to:

- 1. Identify, understand and engage with the fundamental ethical, legal, and social issues pertinent to the practice of genetics in medicine
- 2. Discuss and understand case studies raising ethical, legal and social issues pertaining to the use of genetics in medicine
- 3. Utilize their knowledge to analyze scenarios that may arise in this field in the future

Teaching and Learning Methods

This course will be taught using a combination of lectures by experts in the field and interactive class discussion. Relevant reading materials selected from academic and scientific literature will be assigned in advance of each class. Students will be expected to read all assigned materials and prepare written commentary as described below.

COURSE POLICIES

Attendance

Attendance is mandatory and attendance will be taken (via Zoom/Canvas) at every class meeting. Excused absences are those which the instructor has approved for medical reasons, work, work-related travel, or other unavoidable emergency situations. Situations **not** qualifying as excuses for absence from class include: vacations, traffic, and inclement weather (as long as the university has not canceled classes).

Students may miss up to **two** class sessions without penalty if prior approval from the instructor is granted. If any class sessions are missed, <u>with permission of the instructor</u>, the student will be required to submit additional written assignments covering the missed class material. If a student misses class <u>without</u> the prior approval of the instructor, the student's participation grade will be reduced (see below), and no make-up work will be permitted.

If **more** than two class sessions are missed, <u>with or without</u> permission of the instructor, the student cannot receive credit for completing the course.

Announcements

The instructors will make class announcements, including changes to the schedule, readings and class cancellations (which should be rare) via email (addressed to whatever email account is linked to your university Canvas account). You are responsible for checking your email regularly and reading all announcements. The instructors may also make administrative announcements at the beginning of class, making your arrival in class on time particularly important.

Online Class Protocol

Class Start: Class will begin at 5:00 pm MST sharp. We will not delay to allow students to join late. Accordingly, please join each class session prior to the scheduled beginning of class to avoid missing important announcements that will be made immediately upon the commencement of class. Joining class more than 5 minutes late (as recorded by Zoom/Canvas) will result in a reduction of your participation grade for that class.

Breaks: You must remain in class during the entire 2-hour class period. There will not be a formal class break, but you may of course temporarily leave as needed during class to attend to personal needs.

Camera ON: Your camera should be ON during the entire class period.

Screen: You should join the class from a <u>computer</u> or <u>tablet</u> that enables you to read PowerPoint slides. Joining by smartphone or other mobile device is not preferred.

Mute: Mute your microphone while you are not speaking.

Questions: Students should raise their hands by using the "Raise My Hand" button in the Participants list.

Chat: You may use the "chat" feature on Zoom, either to the entire class, to the instructors or to individuals. Please note that "Private" chat IS NOT PRIVATE. The entire transcript of all private chats will be recorded as part of the class session and posted on Canvas. So do not say anything in private chat that you don't want the entire class, including your instructors, to read.

Appropriate Language: You should not post any comment in chat that you would not ordinarily speak aloud in class, which includes anything that is offensive or in violation of University discrimination, hate speech and similar policies. Be polite and courteous in all of your interactions with other students, guest speakers, and your instructors.

Written Assignments

A set of questions will be posted on Canvas at least one week prior to each class session, other than Class 1. The questions will cover the reading material and topic for the corresponding class.

Each student is required to submit responses to 10 of the 11 sets of pre-class questions. Responses are due no later than the beginning of the corresponding class.

Content. Your response to each question should be at least 75 words. In formulating responses, you should feel free to draw on your own personal experiences, other classes, and current news stories/developments. There may be points on which you wish to challenge the authors, or you may be aware of relevant issues that were not addressed. You are welcome to consult external sources and criticism of the assigned materials or the perspectives expressed therein, provided that you properly cite and reference all external materials.

Evaluation. The 10 written assignments represent 80% of your grade in this class (8% per assignment). Your responses will be graded on the basis of completeness, responsiveness to the question, demonstration that you have completed and understood the reading, and overall coherence and logic. Please write in complete sentences. All University rules and regulations regarding academic misconduct and plagiarism apply to your assignments (see University Policies, below).

Submission Mechanics. The assignment for each class session is due no later than the beginning of the scheduled class session. Submissions prior to this deadline are welcome. Submissions will be made through Canvas as explained during Class 1.

All assignments must be submitted as Microsoft Word documents. Each assignment should state the student's name, the name of the class, the date submitted, and the Class number. Documents should be paginated, with the student's name on each page.

Late assignments will not be accepted. If an illness or other documented emergency situation with a duration of more than one week prevents you from submitting an assignment by the deadline, and you notify the instructors in advance of the submission deadline, an alternative writing assignment may be offered to make-up the missed assignment.

Class Participation

You will be graded on the quality of your class participation and discussion. This component constitutes 20% of your final grade.

Class participation consists of the following minimum requirements: attendance for the entire class period (as recorded by Zoom/Canvas), arriving on time at the beginning of class, reading and viewing all assigned materials prior to class, being prepared to discuss any of the assigned materials and topics of discussion in class, active participation in class exercises, engaging in and contributing to thoughtful class discussion, and demonstrating professional conduct and respect for the opinions of your peers. It is expected that every student will make a **meaningful contribution** to the discussion in each class session. By "meaningful", you must demonstrate a thorough understanding of the assigned readings and apply that knowledge to the discussion of the case studies or lecturer's presentation.

Your participation grade will be reduced for tardy arrival in class. You will receive no participation credit if you miss a class without prior permission of an instructor. If you miss class with permission of the instructor, you may make-up participation credit via an alternative written assignment given by the instructor.

Grading

Your class grade will be based on the following:

Class Attendance and Discussion: 20%

Written Assignments: 80%

Letter grades for this course correspond with the following numerical scale:

A >93%

A- 90-92.9%

B+ 87-89.9%

B 83-86.9%

B- 80-82.9% C+ 77-79.9% C 73-76.9% C- 70-72.9% F Below 70%

MD ID 7251 students will be graded using the following scale:

Pass 70-100% Fail <70%

SPRING 2021 CLASS SCHEDULE

All classes will be held from **5-7 p.m. MST** on the indicated date.

A Zoom link will be made available to all students via Canvas.

Class	Date	Topic(s)*	Instructor(s)
1.	Jan. 20	Introduction to Law and Ethics	Contreras
2.	Jan. 27	Use of DNA in Criminal Proceedings	John Butler (NIST)
3.	Feb. 3	Liability for Genetic Diagnosis	Gary Marchant (ASU)
4.	Feb. 10	Health Data Privacy	Leslie Francis (Utah)
5.	Feb. 17	Genetics and Discrimination	Jessica Roberts (U.
			Houston)
6.	Feb 24	Regulation of Genetics - FDA	Erika Leitzen (U. Mo.)
7.	Mar. 10**	Healthcare Reimbursement	Rachel Sachs (Wash U)
8.	Mar. 17	Ownership of Bodies, Genes and Data	Contreras
9.	Mar. 24	Patents I	Contreras
10.	Mar. 31	Patents II	Contreras
11.	Apr. 7	Gene Editing	Jacob Sherkow (U. III.)
12.	Apr. 14	Data Sharing	Contreras

^{*} Topics/Speakers may be rearranged or altered for scheduling purposes.

^{**} Though it is not recommended, students enrolled in LAW 7906 may miss this class as one of their two excused absences, given the College of Law "non-spring-break" Spring reading period.

UNIVERSITY POLICIES

- 1. Safety Policy Statement: We will listen and believe you if someone is threatening you. 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.
- 2. 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 the class, reasonable prior notice needs to be given to the Center for Disability Services (CDS), 162 Olpin Union Building, 581-5020 (V/TDD). CDS will work with you and the instructor to make arrangements for accommodations. All written information in this course can be made available in alternative format with prior notification to the Center for Disability Services. Students with a documented disability and students seeking to establish the existence of a disability and to request accommodation are required to meet with the CDS Director. The CDS will work closely with eligible students and the Office of Professionalism, Evaluation & Learning to make arrangements for approved accommodations. The School of Medicine and CDS maintain a collegial, cooperative, and collaborative relationship to ensure compliance with federal and state regulations for students with disabilities. The SOM Director of Learning Resources, Steve Baumann (1C103 SOM Dean's Office, 587-3671, or (steven.baumann@hsc.utah.edu), serves as the liaison between the School of Medicine and the Center for Disability Services.
- 3. 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 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. For off-campus resources, contact the Utah Domestic Violence Coalition at 1-800-897-5465. To report to the police, contact the Department of Public Safety, 801-585-2677(COPS).
- **4. Drop/Withdrawal**. Please check the University of Utah's academic calendar for information pertaining to drop and withdrawal dates. Withdrawing from a course and other matters of registration are the student's responsibility. http://registrar.utah.edu/academic-calendars/
- **5. Wellness Statement**. Personal concerns such as stress, anxiety, relationship difficulties, depression, cross-cultural differences, etc., can interfere with a student's ability to succeed and thrive at the University of Utah. For helpful resources contact the Center for Student Wellness at www.wellness.utah.edu or 801-581-7776.

- **6. Veterans Center**. If you are a student veteran, the University of Utah has a Veterans Support center located in Room 161 in the Olpin Union Building. Please visit their website for more information about what support they offer, a list of ongoing events and links to outside resources: http://veteranscenter.utah.edu.
- 7. LGBT Resource Center. If you are a member of the LGBTQ community, the instructors want you to know that this class is a safe zone. Your views will be treated with respect and attention. Additionally, the University of Utah has an LGBT resource center on campus. It is located in Room 409 of the Olpin Union Building. You can visit its website to find more information about the support it can offer, a list of events through the center and links to additional resources: http://lgbt.utah.edu.
- 8. Student Names and Personal Pronouns: Class rosters are provided to the instructor with the student's legal name as well as "Preferred first name" (if previously entered by you in the Student Profile section of your CIS account, which managed can be managed at any time). The instructors will use reasonable efforts to refer to you by the name and pronoun that you specify in advance in writing. Please advise the instructors of any name or pronoun changes that occur during the course of the semester. If you need any assistance or support in this regard, please reach out to the LGBT Resource Center. https://lgbt.utah.edu/campus/faculty_resources.php
- 9. Learners of English as an Additional/Second Language. If you are an English language learner, please be aware of several resources on campus that will support you with your language and writing development. These resources include: the writing Center (http://writingcenter.utah.edu); the Writing Program (http://writing-program.utah.edu); the English Language Institute (http://continue.utah.edu/eli).
- 10. Diversity/Inclusivity Statement: It is the instructors' intent that students from all diverse backgrounds and perspectives be well served by this course, that students' learning needs be addressed both in and out of class, and that the diversity that students bring to this class be viewed as a resource, strength and benefit. It is the instructors' intent to present materials and activities that are respectful of diversity: gender, sexuality, disability, age, socioeconomic status, ethnicity, race, and culture. Your suggestions are encouraged and appreciated. Please let the instructors know ways to improve the effectiveness of the course for you personally or for other students or student groups. In addition, if any class meetings conflict with your religious events, please let the instructors know as soon as possible so that alternative arrangements can be considered.

11. Class Recording

Note that each session of this class will be video recorded. This includes both the lecture/presentation as well as class discussion. All recordings will be posted on Canvas following the relevant class so that you may refer to them in your studies. The University of Utah reserves the right to re-use all recorded content in its discretion.

12. Student Code

The Student Code for the University of Utah applies to this class. It can be found at: http://regulations.utah.edu/academics/6-400.php.