

Implications of the New Genetics
AKA: Ethical, legal, social implications (ELSI) of Genetics
01:447:354:01
Fall 2017
T/F 10:20-11:40am
Rutgers Cinema Room 3

Instructor:

Dr. Karen Schindler
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LSB 222
848-445-2563

Office hours:

To accommodate everyone's schedules, please email me for an appointment.
*The door is under swipe-card access; knock loudly or call my office # to get in!

Course emphasis:

Science is not separate from your life. In the 21st century, information about genetics is increasing almost exponentially and changing rapidly. Ideas that were science fiction only a few years ago are now possible. But, many social, ethical and legal systems are not advancing at the same pace and are influenced by biological ideas that are no longer valid.

This course fulfills elective requirements for Biological Science and Genetics majors. I will present information from a historical perspective and review emerging genetic technologies. You will be *expected* to understand the basics of genetics and molecular biology: Mendelian inheritance, central dogma, PCR, cloning, etc. If you need review material and supplemental reading please see me. This course also satisfies the SAS Core Curriculum Goal of 21st Century Challenges. You will therefore be expected to apply materials taught in class to current social issues.

Course goals:

1. Students will learn terms, concepts and theories behind genetic technologies and apply them to social, legal and ethical issues.
2. Students will use information and ideas discussed in class to critically analyze published articles in genetics.
3. Students will research the social, legal and ethical implications of a genetic principle/technology. They will understand and describe ethical considerations from multiple sides of an issue.
4. Students will become knowledgeable and well-versed in current events surrounding emerging genetic technologies.
5. Students will critically analyze ethical scenarios using ethical principles.
6. Students will learn approaches in describing complex genetic technologies and their implications to a lay audience.

Course Policies:

1. Academic Integrity

Violations of academic integrity include: cheating, fabrication, plagiarism, denying others access to information or material, and facilitating violations of academic integrity. All of these violations will not be tolerated. In accordance with departmental and University Policy, violations of academic integrity will immediately be referred to the dean. Please review the following university website for specific information regarding academic integrity: <http://academicintegrity.rutgers.edu/integrity.shtml>
<http://academicintegrity.rutgers.edu/resources-for-students>

2. Attendance Policy

Given the format and content of this class, attendance is mandatory. Attendance will be taken during each class. If you are absent from class, this is to be reported using the University absence reporting website (<https://sims.rutgers.edu/ssra/>). Indicate the date and reason for absence for my records. This must be reported before the start of class. If you are absent from class, you cannot receive a participation point for that day. Students with more than 3 absences will not be exempt from the final, regardless of their grade. **Students will not receive credit for attendance if they are more than 20 minutes late to class.**

3. Technology policies

We will frequently use electronic devices (smart phone, tablet, laptop) for participating in *TopHat* activities. However, this is not to be abused! Cell phones are to be silenced during class. Laptops are permitted in class for academic purposes as they relate to this course. If a student is found to be using their laptop or device for purposes other than this course (use of other websites, social media), the student will be asked to put away the device for the remainder of class and must discuss this violation with the professor after class. Use of computers or devices for non-course purposes are distracting and disrespectful.

4. Demonstrating Respect

One of the exciting aspects of this course is the discussion that will be generated by the topic content. We will learn that ethical topics, by definition, do not always have a right or wrong answer. We will examine different ways to approach these scenarios and attempt to understand what may factor into an individual's perspective on the matter. Thus, I do not expect (or want) students in the class to always agree with one another. However, various opinions, values, perspectives, etc. must be respected and dealt with in a professional and civil manner.

Class requirements:

1. Participate, participate, participate. One of the reasons that the public often misjudges science is a lack of active dialogue on the part of scientists. My goal is to get you comfortable with discussing these hotly debated topics in a public setting (the classroom) while being respectful of opposing opinions. If you are not an active participant, your chances of receiving an “A” are slim. **Note that if you miss class, you also miss participation points.**

2. TopHat. New this semester! This activity will require 2 things: a subscription to TopHat and a wifi-enabled device such as smart phone, tablet, or laptop. **Please purchase a subscription to TopHat (\$26).** I will provide the information on the first day of class and in Sakai. This will allow us to conduct on-the-spot opinion polls, collect comments to take a pulse on what your classmates are thinking about a topic, and to take attendance. Be patient with me on this, I'll be learning it as we go.

3. 3 X 5 index cards: You will need to supply these. At the end of each class, you will be given 1-2 questions to answer on a card. **Put your name in the upper right hand corner of the card and turn it in as you leave.** This serves as a way for me to gauge any misunderstandings of the material, to challenge you with a thought-provoking, no-right-or-wrong-answer type question, and to take class attendance. As you turn in your card, you will also remind me if you spoke during that class to receive your participation credit.

4. Access to Sakai and email: All quizzes, opinion surveys, emails, reading assignments and blog entries will occur through the class Sakai site. There are a lot of moving parts and deadlines in this class that are easy to miss if you are not organized. **Make sure you have Sakai sending notifications to an email that you regularly check.** I also highly recommend setting up an electronic calendar (Google, MS Outlook, etc.) that sends you assignment alert notifications if you do not currently have a reliable system.

Textbooks:

There is no textbook for this course. Instead, I will be providing reading material for each lecture through Sakai. The readings are listed in the syllabus and will be in folders by month and lecture date in Resources.

TopHat:

We will be using the Top Hat (<http://www.tophat.com>) classroom response system in class. You will be able to submit answers to in-class questions using Apple or Android smartphones and tablets, laptops, or through text message. You will need to purchase a subscription to TopHat for the class (\$26/semester).

You can visit the Top Hat Overview (<https://success.tophat.com/s/article/Student-Top-Hat-Overview-and-Getting-Started-Guide>) within the Top Hat Success Center which outlines how you will register for a Top Hat account, as well as providing a brief overview to get you up and running on the system.

By the 2nd class meeting (9/8), all students must be registered. An email invitation will be sent to you, but if don't receive this email, you can register by simply visiting our course website: <https://app.tophat.com/e/309954>

Note: our Course Join Code is 309954

Top Hat will require a paid subscription, and a full breakdown of all subscription options available can be found here: www.tophat.com/pricing.

Should you require assistance with Top Hat at any time, due to the fact that they require specific user information to troubleshoot these issues, please contact their Support Team directly by way of email (<mailto:support@tophat.com>), the in app support button, or by calling 1-888-663-5491.

Useful Websites:

Search engine for primary scientific literature: [PubMed Central](http://pubmedcentral.ncbi.nlm.nih.gov/)

Scientific News:

Nature News (<http://www.nature.com/news/>)

Science Magazine News (<https://www.sciencemag.org/news>)

New York Times (<http://www.nytimes.com>)

National Public Radio (<http://www.npr.org>)

Genetic analysis projects and companies:

(Note: inclusion is not an endorsement)

Ancestry.com (<http://www.ancestry.com>)

23andme (<http://www.23andme.com>)

Color Genomics (<http://www.getcolor.com>)

Counsyl (<http://www.counsyl.com>)

Athletigen (<http://www.athletigen.com>)

The ClinSeq Project (<http://www.genome.gov/20519355>)

Genomes2People (<http://www.genomes2people.org>)
The Personal Genome Project (<http://www.personalgenomes.org>)
The 100,000 Genomes Project (<http://www.genomicsengland.co.uk>)
Exome Aggregation Consortium (<http://exac.broadinstitute.org>)

Public policy and advocacy:

The Genetic Alliance (<http://www.geneticalliance.org>)
Center for Genetics and Society (<http://www.geneticsandsociety.org>)
Council for Responsible Genetics (<http://www.gene-watch.org>)
Search engine to explore Congressional bills (<http://www.govtrack.us>)
Genetic Literacy Project (<https://geneticliteracyproject.org>)

Grading:

You will be assessed through multiple mechanisms. 70% of your grade will be based on individual assessment and 30% of your grade will be based on group work. The breakdown is as follows:

- 20% Class participation:** Class participation includes: verbal and written TopHat participation, peer evaluations of student presentations, and participation in anonymous surveys. *If you are absent from class, you miss an opportunity for participation points.*
- 20% Blog entries:** You will be required to write an on-line blog through Sakai. Submissions are due by midnight on the Friday after the assignment is given. You will have 5 blog assignments with ~2 weeks to craft each blog. I will choose blogs at random to grade; you will receive 4 blog grades during the semester. Responses and scores will be emailed to you within 1 week of the submission. See Resources section for examples and a rubric for evaluation.
- 15% Online reading quizzes:** Short quizzes will be given through Sakai to ensure that you understand the reading material. **You will have 2 chances to submit your answers to achieve 100%.** Quizzes will be released at the end of a class (12 pm) and will always close at 8 am the day of class. There are 13 quizzes scheduled (not including the syllabus quiz). I will drop the lowest score, because I understand that things happen.
- 10% Final exam:** The final will be similar to our in class “Journal Club” discussion and blog assignments 3 and 4. You will be assigned a scientific journal article with an accompanying news article on the last day of class. You can bring it with you to the exam, along with any notes you may take regarding the background, methods, and data (unlimited page numbers). The exam will consist of a mixture of multiple choice and short answer questions. **Students with a course grade of 94% or higher prior to the final are exempt from the exam, unless you have missed more than 3 classes (regardless of course grade). Exempt students will receive an email confirmation.**
- 5% Blog discussions:** Part of blogging is the dialogue between the blogger and their audience. You will be assigned classmate’s blogs to read and to provide comments 2 times during the semester. The dialogue you wish to initiate is up to you, but you must respect the blogger’s position. You can play the “devil’s advocate” or provide alternative reading materials if you disagree with their position, but again, in a respectful way. If you like a blog post, state why (i.e.- just saying “great job” will not get you credit for this activity).
- 30% Group case study**

You will be pre-assigned a group after the drop-add period and I will try my best to follow student “preferences” for 1 group member. I will approve topics via a written **proposal due on 10/20/17**. Use proposal form on Sakai (in resources).

A. Presentation (60%): The group will present a 25-minute oral presentation on a case study that is a current event. There will be a 10-minute question/discussion session

following your presentation. The PowerPoint presentation must be given by each group member – everyone must take a turn speaking. Given the relatively short length of the presentation, you are encouraged to select a fairly specific topic to allow time to provide a thorough examination of the topic. For example, “Genetic Testing” would likely be too broad to cover in 25 minutes. “Ethical considerations of non-invasive prenatal testing” may be a more reasonable topic. We will randomly select the order of group presentations in November.

Finally, as a group, you must write up a summary of the roles contributed to the project. This summary sheet must be signed by all group members in order to receive credit for your project.

Your presentation will be evaluated by me (50%) and by your classmates (averaged and weighted 50%), and weighted as 60% of the case study grade.

B. Self/Peer Evaluation (10%): Each member is to complete the 1 page self and peer evaluation question form found in Sakai. This is due, along with the paper, the day of your presentation. Please keep your evaluations confidential. If there is a group member who has not been contributing to an equal extent, this is your ONLY opportunity to voice this issue so that I can consider modifying that member’s group grade. I will NOT accept complaints outside of this form.

C. Paper (30%): You will submit a 1-2 page independently written paper on your topic following the outline guidelines in Sakai. **This paper is due the day of your presentation.**

DATE	TOPIC	READINGS	ASSIGNMENTS (DUE DATE)	WHAT'S DUE TODAY?
TUES 9/5	Intro to course; Scientific literacy and public perception	1. Syllabus 2. Public perceptions 3. US public wary	1. Blog 1: Literacy (11:59pm 9/15) 2. Syllabus quiz (8am 9/8)	
FRI 9/8	Intro to ethics; Intro to blogging	1. Fact sheet 23 (pg. 1-3) 2. Social vs Ethical Issues 3. http://matt.might.net/articles/my-sons-killer/ 4. https://genomethicsblog.org/2017/05/17/legal-duty-to-share-genetic-information-goes-to-trial/ 5. http://sage.buckinstitute.org/the-promise-of-personalized-medicine/	1. Reading quiz (8am 9/12)	1. Syllabus quiz
TUES 9/12	Reprogenetics: Biology behind the ART	1. Bioethics and Embryology (pg. 64-79) 2. Feuer 2013 (pg.189-195)	1. Reading quiz (8am 9/15)	1. Reading quiz
FRI 9/15	Reprogenetics: PGD and eugenics	1. Bioethics and Embryology (pg. 215-225) 2. Silver 2000 3. Neumayr 2005 4. Ethics of PGD	1. Blog 2: ART (11:59pm 9/29) 2. Reading quiz (8am 9/19)	1. Blog 1: Literacy 2. Reading quiz
TUES 9/19	Reprogenetics: Epigenetics and ART	1. Epigenetics TIME mag 2. ART risks (pg. 3-7) 3. Parenting before conception 4. Grandma's experiences	1. Reading quiz (8am 9/22)	1. Reading quiz
FRI 9/22	Reprogenetics: Journal Club	1. Ecker 2004 2. BBC news 3. Nature News 4. Optional: How to read a scientific paper	1. Reading quiz (8am 9/26)	1. Reading quiz
TUES 9/26	Reprogenetics: 3 parent embryos	1. Power of 3 2. Ethics of mito transfer 3. Darnovsky 4. 3 parent embryo fail	1. Reading quiz (8am 9/29)	1. Reading quiz
FRI 9/29	Reprogenetics: germline modification	1. Crispr, the disruptor 2. Genetically engineered babies 3. Tomorrow's children 4. Research in humans	1. Blog 3: ART JC (11:59pm 10/13) 2. Reading quiz (8am 10/3)	1. Blog 2: ART 2. Reading quiz

DATE	TOPIC	READINGS	ASSIGNMENTS (DUE DATE)	WHAT'S DUE TODAY?
TUES 10/3	Reprogenetics: Stem Cells and Cloning	1. Hyun 2010 2. Kiskinis and Eggan 2010 3. Hyun 2014 4. Human stem cells via cloning	1. Comment on 2 blogs (10/10)	1. Reading quiz
FRI 10/6	Genetics and genomics: DIY science diagnosis	1. Life Hackers 2. DIY Crispr		NO QUIZ!
TUES 10/10	Genetics and genomics: Genetic counseling and cancer genetic- Jessica Joines	1. Offit ELSI 2. Caplan Jolie 3. JGC essentials	1. Case studies (10/13)	1. Blog 2 peer comments 2. NO QUIZ!
FRI 10/13	Genetics and genomics: Genetic counseling case studies- Jessica Joines	1. Case studies	1. Blog 4: DIY JC (11:59pm 10/27) 2. Reading quiz (8am 10/17)	1. Blog 3: ART JC 2. Case study discussion in class
TUES 10/17	Genetics and genomics: Biological specimen and sequence ownership- Henrietta Lacks	1. Biospecimen policy 2. Deal done 3. The sequel		1. Reading quiz
FRI 10/20	Genetics and genomics: Movie-Twitch	1. Huntington	1. Reading quiz (8am 10/24)	NO QUIZ! 1. Final group project proposal
TUES 10/24	Genetics and genomics: Precision medicine and privacy	1. Cancer Genomics 2. NEJM Precision Medicine 3. The genome hacker	1. Reading quiz (8am 10/27)	1. Reading quiz
FRI 10/27	Genetics and genomics: Direct to consumer genetic testing	1. DTC testing 2. NYT DTC Labs 3. DTC Genetics 4. What's next?	1. Blog 5: Open (11:59pm 11/10)	1. Reading quiz 2. Blog 4: DIY JC
TUES 10/31	Genetics and genomics: International implications- Francis Barchi	TBA	1. Reading quiz (8am 11/3)	NO QUIZ!

DATE	TOPIC	READINGS	ASSIGNMENTS (DUE DATE)	WHAT'S DUE TODAY?
FRI 11/3	Genetics and genomics: DNA Patents	1. Williams Biotech Briefing 2. Allen 2001 3. Perkel 2013 4. Intellectual property 5. Myriad data fight	1. Reading quiz (8am 11/7)	1. Reading quiz
TUES 11/7	Genetic modification of food: History, technology, glyphosate	1. Editing the mushroom 2. GMO 3 3. GM report 4. In the pipeline (pg1-5)		1. Reading quiz
FRI 11/10	Group work		1. Reading quiz (8am 11/14) 2. Comment on 2 blogs	1. Blog 5: Open 2. NO QUIZ
TUES 11/14	Genetic modification of food: Benefits, risks, labels	1. GM Safety 2. Wash post 3. GMO 8 4. Refusing organic	1. Reading quiz (8am 11/17)	1. Reading quiz
FRI 11/17	Forensic Genetics	1. Idov 2011 2. Murphy 2013 3. NJ laws 4. NYT Zimmer 5. Technology		1. Blog peer comments 2. Reading quiz
TUES 11/21	NO CLASS HOLIDAY SCHEDULE			
WED 11/22	Group Case study presentations			1. Presentation evaluations
FRI 11/24	NO CLASS Thanksgiving Break			
TUES 11/28	Group Case study presentations			1. Presentation evaluations
FRI 12/1	Group Case study presentations			1. Presentation evaluations
TUES 12/5	Group Case study presentations			1. Presentation evaluations
FRI 12/8	Group Case study presentations			1. Presentation evaluations
TUES 12/12	Group Case study presentations			1. Presentation evaluations
FRI 12/22	FINAL EXAM	< 94% or > 3 classes missed	TBA	

Important dates

1. Journal entries 6 Fridays by MIDNIGHT
2. Group project proposals due 10/20/17
3. **Final exam 12/22 at 8am** (unless you have a 94% or above and haven't missed more than 3 classes)

Refer to the Sakai course calendar for due dates if you are confused!

Supplemental instructional materials found in Sakai "resources" folder

1. What to do if adding course
2. Examples of good and bad blog entries
3. Examples of good and bad case study project topics
4. Final exam from 2015
5. Student evaluation grading forms
6. Group numbers and members' names (after drop/add)

Letters of recommendation

I will only write letters of recommendation for students that I know **VERY** well. These individuals typically (a) participate regularly in class and attend office hours, (b) talk Genetics with me outside of the classroom, and (c) are Genetics aficionados (i.e. the top 25% of the course which is usually above a 95%). Once I agree to write a letter, I will send you detailed instructions. It will require some writing on your part. Advance notice is required, and at minimum, I will need 3 weeks time to craft an effective letter.

Student-Wellness Services:

Just In Case Web App

<http://codu.co/cee05e>

Access helpful mental health information and resources for yourself or a friend in a mental health crisis on your smartphone or tablet and easily contact CAPS or RUPD.

Counseling, ADAP & Psychiatric Services (CAPS)

(848) 932-7884 / 17 Senior Street, New Brunswick, NJ 08901/ rhscaps.rutgers.edu/

CAPS is a University mental health support service that includes counseling, alcohol and other drug assistance, and psychiatric services staffed by a team of professional within Rutgers Health services to support students' efforts to succeed at Rutgers University. CAPS offers a variety of services that include: individual therapy, group therapy and workshops, crisis intervention, referral to specialists in the community and consultation and collaboration with campus partners.

Violence Prevention & Victim Assistance (VPVA)

(848) 932-1181 / 3 Bartlett Street, New Brunswick, NJ 08901 / vpva.rutgers.edu/

The Office for Violence Prevention and Victim Assistance provides confidential crisis intervention, counseling and advocacy for victims of sexual and relationship violence and stalking to students, staff and faculty. To reach staff during office hours when the university is open or to reach an advocate after hours, call 848-932-1181.

Disability Services

(848) 445-6800 / Lucy Stone Hall, Suite A145, Livingston Campus, 54 Joyce Kilmer Avenue, Piscataway, NJ 08854 / <https://ods.rutgers.edu/>

The Office of Disability Services works with students with a documented disability to determine the eligibility of reasonable accommodations, facilitates and coordinates those accommodations when applicable, and lastly engages with the Rutgers community at large to provide and connect students to appropriate resources.

Scarlet Listeners (732) 247-5555 / <http://www.scarletlisteners.com/>

Free and confidential peer counseling and referral hotline, providing a comforting and supportive safe space.