

**Implications of the New Genetics**  
**AKA: Ethical, legal, social implications (ELSI) of Genetics**  
**01:447:354:01/02**  
**Fall 2019**  
**M/H 10:20-11:40am**  
**Tillett 204**

**Instructor:**

Dr. Karen Schindler  
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**Office hours:**

By appointment, please email

**Learning Assistants:**

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**Course Grading Assistant:**

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**Course emphasis:**

*Science is not separate from your life.* In the 21<sup>st</sup> 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social, ethical and legal systems are not advancing at the same pace and are influenced by biological ideas that are no longer valid.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 21<sup>st</sup> 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 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.
3. Students will become knowledgeable and well-versed in current events surrounding emerging genetic technologies.
4. Students will critically analyze ethical scenarios using ethical principles.
5. 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. Therefore, there are no formal excused absences. Attendance will be taken during each class. If you must miss a 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.

*Please note the following:*

**\*\*If you are absent from class, you cannot participate that day. Therefore, do not complete the class contribution form for that day\*\***

**\*\*Students will not receive credit for attendance if they are more than 15 minutes late to class. \*\***

### 3. Technology policies

We will frequently use electronic devices (smart phone, tablet, laptop) for participating in *Poll Everywhere* 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 contributor, your chances of receiving an “A” are slim. You will be responsible for recording your class contribution for each class via the [Google document form link](#) that accompanies the exit ticket. You will be evaluated on **quantity and quality** of your contributions. Therefore, please provide sufficient details regarding your contribution in your response. This is described in further detail in the rubric.

**Note that if you miss class, you also miss participation/contribution opportunities.**

**2. Poll Everywhere:** This activity will require 2 things: a subscription to Poll Everywhere and a wifi-enabled device such as smart phone, tablet, or laptop. Please purchase a subscription to Poll Everywhere (\$14). I will email you a link to sign up. This will allow us to conduct on-the-spot opinion polls and to take attendance.

**3. Exit ticket:** At the end of each class, you will be given a question to answer using Google Forms. **This must be completed before 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, to take class attendance, and record class contribution details. <https://forms.gle/w6yh9R7VMMSeVezt9>

**4. Access to Canvas:** All quizzes, emails, reading assignments and paper decisions will occur through the class Canvas 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 Canvas sending notifications to an email that you check daily.** 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.

**5. Wordpress:** You will complete blog assignments using a course Wordpress site (<http://www.ruelsigenetics2019.com/>). You will receive an emailed invitation that you must accept to use the site for these assignments.

**6. Optional: Twitter account:** Find something interesting during class or on your own that is related to class? Tweet to your personal twitter account and tag **#RUELSIGEN**. This is also a good way to increase your class contribution score (if you record it on your contribution form).

## 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:

**15% Class contribution:** Class contribution includes: contribution log evaluation, peer evaluations of student presentations, and participation in polls. You will be evaluated on the **quantity and quality** of your contributions. You will be responsible for tracking your contributions for each class in the Google document form at this link: <https://forms.gle/w6yh9R7VMMSeVezt9>. These evaluations will occur at the end of each month of the semester. Please refer to the class contribution rubric in resources for grade category descriptions. *If you are absent from class, you cannot have a contribution for that day.*

**OPTIONAL:** Tweet about the class, things you learn and/or read as a way to contribute using **#RUELSIGEN**. This is a great way to tap into the professional Bioethics world and I highly recommend giving it a try. Make sure to include this contribution in your google form.

**25% Blog entries:** You will be required to write blogs using Wordpress at this link: [ruelsigenetics2019.wordpress.com](http://ruelsigenetics2019.wordpress.com). You will receive an email invitation to the blog that you must accept to be able to post. The class site is set to private so no one other than me and your classmates can view your posts. You are welcome to take your posts and use them for your own open access blog site.

You will have 4 blog assignments. Submissions are due by midnight on the due date.

You will receive a score sheet and feedback for each graded blog. See Files section for examples of high scoring blogs and the evaluation rubric.

**5% Blog peer commenting:** Part of blogging is the dialogue between the blogger and their audience. You will be assigned classmates' blogs to read and to provide comments.

**10% Online reading quizzes:** Short quizzes will be given through Canvas. **You will have 1 chance to submit your answers** and will receive answer feedback

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 11 quizzes including the syllabus quiz. The lowest score will be dropped at the end of the semester.

**15% Genetics in the news:** Topics in this course are highly relevant to the news cycle and evolve quickly. For example, every semester I have taught this course, the rules and regulations regarding 23 and Me have changed, and Crispr-mediated genome editing was not even a topic in 2013 and in 2018, a scientist edited human embryos that were used for live birth. We now have the advantage in the active learning room to incorporate current events into our course. You and your table will be expected to stay up-to-date on news coverage throughout the semester. For 2 class meetings you will be assigned a news article to discuss as a

group, create an informative power point slide, and then write a 1-page group-based summary. Please see the instructions and rubric for more details.

### **30% Group case study**

You will be assigned a group after the drop-add period. Note that you will remain seated with your group members at the same table for the rest of the semester. I will approve topics via a written **proposal due on 10/17/19**. Use proposal form on Canvas (in Files).

**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.

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 (5%):** Each member is to complete the 1 page self and peer evaluation question form found in Canvas Modules. 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 (35%):** You will submit a 1-2 page independently written paper on your topic following the outline guidelines in Canvas Modules. **This paper is due the day of your presentation.**

### **Textbooks:**

There is no textbook for this course. Instead, I will be providing reading material for each lecture through Canvas. The readings are listed in the syllabus and will be in folders by week in the Modules section.

### **Poll Everywhere**

We will be using the Poll Everywhere 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 Poll Everywhere for the class (\$14/semester). A course link and invitation will be emailed to you. **By the end of drop/add (9/11), all students must be registered.**

### **Useful Websites:**

#### **Scientific News:**

Search engine for primary scientific literature: [PubMed Central](#)

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>)

MIT Technology Review (<https://www.technologyreview.com/>)

#### **Bioethics Journals:**

Wiley Bioethics (<https://onlinelibrary.wiley.com/journal/14678519>)

The Hastings Center Report (<https://www.thehastingscenter.org/publications-resources/hastings-center-report/>)

AJOB (<https://www.tandfonline.com/toc/uajb20/current>)

Journal of Medical Ethics (<https://jme.bmj.com/>)

Journal of Law, Medicine and Ethics (<https://onlinelibrary.wiley.com/journal/1748720x>)

#### **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 analysis projects and companies:**

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>)

DATE	TOPIC	READINGS FOR TODAY	WHAT'S DUE TODAY?	ASSIGNMENTS (DUE DATE)
<b>THURS</b> <b>9/5</b>	Intro to course	1. Syllabus	1. Contribution log	1. Syllabus quiz (9/12)
<b>MON</b> <b>9/9</b>	Scientific literacy and public perception	1. Public perceptions 2. US public wary	1. Contribution log	1. Syllabus quiz (9/12)
<b>THURS</b> <b>9/12</b>	Intro to ethics; Intro to blogging	<b>Read #1-2 to prepare for lecture; View #3-5 to prepare for blog analysis</b> 1. Fact sheet 23 (pg. 1-3) 2. Social vs Ethical Issues 3. <a href="http://matt.might.net/articles/my-sons-killer/">http://matt.might.net/articles/my-sons-killer/</a> 4. <a href="https://genomethicsblog.org/2017/05/17/legal-duty-to-share-genetic-information-goes-to-trial/">https://genomethicsblog.org/2017/05/17/legal-duty-to-share-genetic-information-goes-to-trial/</a> 5. <a href="https://thebiochemistblog.com/2017/08/03/an-introduction-to-gene-editing-and-where-to-learn-more/">https://thebiochemistblog.com/2017/08/03/an-introduction-to-gene-editing-and-where-to-learn-more/</a>	1. Syllabus quiz 2. Contribution log 1.	1. Reading quiz 1 (9/16) 2. Blog 1 "Scientific literacy" (9/26)
<b>MON</b> <b>9/16</b>	<b>Reprogenetics:</b> Biology behind the ART	1. Bioethics and Embryology (pg. 64-79) 2. Feuer 2013 (pg.189-195)	1. Reading quiz 1 2. Contribution log	1. Reading quiz 2 (9/19)
<b>THURS</b> <b>9/19</b>	<b>Reprogenetics:</b> PGD and eugenics	1. Silver 2000 2. Neumayr 2005 3. Ethics of PGD 4. Bioethics and Embryology (pg. 215-225)	1. Reading quiz 2 2. Contribution log	1. Reading quiz 3 (9/23)
<b>MON</b> <b>9/23</b>	<b>Reprogenetics:</b> Epigenetics and ART	1. Epigenetics TIME mag 2. Parenting before conception 3. Grandma's experiences 4. ART risks (pg. 3-7)	1. Reading quiz 3 2. Contribution log	1. Reading quiz 4 (9/26)
<b>THURS</b> <b>9/26</b>	<b>Reprogenetics:</b> Mitochondrial replacement therapy	1. Power of 3 2. Ethics of mito transfer 3. Darnovsky 4. 3 parent embryo fail	1. Blog 1 2. Reading quiz 4 3. Contribution log	1. Reading quiz 5 (9/30) 2. Blog 2 "ART and me" (10/10)
<b>MON</b> <b>9/30</b>	<b>Reprogenetics:</b> Germline modification	1. Crispr, the disruptor 2. Genetically engineered babies 3. Tomorrow's children 4. Research	1. Reading quiz 5 2. Contribution log	1. Reading quiz 6 (10/3)

DATE	TOPIC	READINGS FOR TODAY	WHAT'S DUE TODAY?	ASSIGNMENTS (DUE DATE)
<b>THURS 10/3</b>	<b>Reprogenetics:</b> Stem Cells and Cloning	1. Hyun 2010 2. Kiskinis and Eggan 3. Hyun 2014 4. Human stem cells	1. Reading quiz 6 2. Contribution log	1. News article (10/7)
<b>MON 10/7</b>	<b>Genetics in the News</b>	1. Assigned news article	1. Current event summary 2. Current event powerpoint 3. Contribution log	1. Current event summary (10/7) 2. Current event powerpoint (10/7)
<b>THURS 10/10</b>	<b>Case Studies</b>	Case studies	1. Contribution log 2. Blog 2	1. Reading quiz 7 (10/14) 2. Blog 3 (10/24) 3. Blog peer commenting
<b>MON 10/14</b>	<b>Genetics and genomics:</b> Direct to consumer genetic testing	1. DTC testing 2. NYT DTC Labs 3. DTC Genetics 4. What's next?	1. Reading quiz 7 2. Contribution log	1. Reading quiz 8 (10/17)
<b>THURS 10/17</b>	<b>Genetics and genomics:</b> Precision medicine and privacy	1. Cancer Genomics 2. NEJM Precision Medicine 3. The genome hacker	1. Reading quiz 8 2. Blog peer commenting 3. Contribution log 4. Group final project proposal	1. Reading quiz 9 (10/21)
<b>MON 10/21</b>	<b>Genetics and genomics:</b> Biological specimen and sequence ownership: Henrietta Lacks	1. Biospecimen policy 2. Deal done 3. The sequel	1. Reading quiz 9 2. Contribution log	1. Reading quiz 10 (10/24)
<b>THURS 10/24</b>	<b>Genetics and genomics:</b> DIY science diagnosis	1. Life Hackers 2. DIY Crispr	1. Reading quiz 10 2. Contribution log 3. Blog 3	1. Reading quiz 11 (10/28) 2. Blog 4 "Blogger's choice" (11/7)
<b>MON 10/28</b>	<b>Genetics and genomics:</b> DNA Patents	1. Williams Biotech 2. Allen 2001 3. Perkel 2013 4. Intellectual property 5. Myriad data fight	1. Reading quiz 11 2. Contribution log	TBA
<b>THURS 10/31</b>	<b>Genetics and genomics:</b> Genetic counseling and cancer  Jessica Joines	TBA	1. Contribution log	1. News article

DATE	TOPIC	READINGS FOR TODAY	WHAT'S DUE TODAY?	ASSIGNMENTS (DUE DATE)
MON 11/4	Genetics in the News	1. Assigned news article	1. Contribution log	1. Current event summary (11/1) 2. Current event powerpoint (11/1) 3. Case studies
THURS 11/7	Genetics and genomics: Genetic counseling case studies	1. Case studies	1. Contribution log 2. Blog 4	1. Huntington NYT 2. Blog peer commenting
MON 11/11	Genetics and genomics: Movie-Twitch Melissa Ghandi	1. Huntington NYT	1. Contribution log	1. Peer blogs
THURS 11/14	Blog workshop and awards; Group project work	Blogs	1. Contribution log 2. Blog award recs 3. Blog peer commenting	
MON 11/18	Case study presentations		1. Presentation evaluations 2. Contribution log	
THURS 11/21	Case study presentations		1. Presentation evaluations 2. Contribution log	
MON 11/25	Case study presentations		1. Presentation evaluations 2. Contribution log	
TUES 11/26	Case study presentations		1. Presentation evaluations 2. Contribution log	
THURS 11/28	<b>NO CLASS Thanksgiving Break</b>			
MON 12/2	Case study presentations		1. Presentation evaluations 2. Contribution log	
THURS 12/5	Case study presentations		1. Presentation evaluations 2. Contribution log	
MON 12/9	<b>NO CLASS</b>		Relaxation!	

### **Supplemental instructional materials found in Canvas “Modules” 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. Student evaluation grading forms
5. 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,
- (c) are Genetics aficionados (i.e. **above a 95%** in the course), and
- (d) are carefully tracking their contribution to the class so that we can use specific examples in the letter.

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/](http://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/](http://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–**

Get things off your chest in a non-judgmental, empathetic space facilitated by trained students. Sessions are held Monday-Thursday evenings during the Fall and Spring semesters.

Sign up for information about times and locations at [tinyurl.com/SLGroupSessions](http://tinyurl.com/SLGroupSessions) or email [scarlet.listeners@gmail.com](mailto:scarlet.listeners@gmail.com)