

SEMESTER AT SEA COURSE SYLLABUS

Voyage: Spring 2013

Discipline: Public Health

Course Title: SEMS 3500-103 Genomics and Public Health (Behavioral, Social, and Ethical Issues)

Upper Division

Faculty Name: Mary Ropka, Ph.D., RN, FAAN Professor of Public Health Sciences

Class Meeting Time: B Day 0800 - 0915

Pre-requisites: None.

COURSE DESCRIPTION

Advances in genetics and genomics research present both great opportunities and complex challenges for public health and society. Resulting knowledge and technologies from the laboratory are being applied in health care and people's everyday lives. In order for the potential benefits of genomics to be realized (and unintended harms minimized), numerous behavioral, social, and ethical issues will need to be understood and addressed. This cutting-edge course will employ a blend of lecture/discussions, group discussions, multimedia presentations, and written and oral application assignments to explore these issues as they relate to genomics and public health. They include: ethical issues raised in research and health care; behavioral and social impact for individuals and families of genetic and genomic testing; public knowledge and attitudes about genetics and genomics; educational and informational interventions to enhance genetic literacy; and emerging issues in the field (e.g., direct-to-consumer marketing of genomic tests, pharmacogenomics). Perspectives of different course topics will be enriched by incorporating popular press books in application assignments.

COURSE OBJECTIVES

After completing this course, students should be able to:

1. Understand basic genomic information as it pertains to public health, and related behavioral, social, and ethical issues.
2. Use diverse literature and research sources to gain understanding of selected behavioral, social, and ethical issues in public health genomics.
3. Discuss important behavioral, social, and ethical dimensions of moving genomics discoveries into healthcare and society.
4. Identify potential risks and benefits of genomics in public health.
5. Identify areas for future research and health care related to behavioral, social, and ethical aspects of public health genomics

REQUIRED TEXTBOOKS

AUTHOR: Francis Collins

TITLE: The Language of Life: DNA and the Revolution in Personalized Medicine

PUBLISHER: Harper Perennial; 1 edition (January 18, 2011)

ISBN #: 978-0061733185

DATE/EDITION: 2011/1st edition

COURSE DESCRIPTION

TOPICAL OUTLINE OF COURSE:

UNIT ONE: BACKGROUND AND OVERARCHING ISSUES

- Overview of past to present regarding genetics & genomics and public health

- Family history; Genetic counseling/genetic testing
- Genetics and race
- Public understanding of genetics and genomics; Genetic literacy

UNIT TWO: GENETIC AND GENOMIC TESTING APPLICATIONS

- Newborn screening
- Predictive testing for Huntington's disease
- Susceptibility testing: Breast cancer and Alzheimer's disease
- Direct-to-consumer (DCT) genomic testing

UNIT THREE: EMERGING ISSUES IN GENETICS/GENOMICS

- Gene - Environment interactions in complex diseases; Epigenetics
- Pharmacogenomics
- \$1,000 Genome

CLASS SCHEDULE:

Between Ensenada &Hilo]

Day 1:

- Introduction to course and course requirements/evaluation
- Review of course textbook and accessing other resources
- Introduction to course-related Field Lab

Reading Assignment:

None

Assignment Due Today:

None

Day 2:

- PBS NOVA "Cracking Your Genetic Code" [download from <http://video.pbs.org/video/2215641935/>] (53 min). (Accessed 10/11/12)
- As you watch, write down any potential behavioral, social, or ethical issues that you recognize.

Reading Assignment:

- Quackenbush, J. (2011). Chapter 1: Back to Basics (pp. 21 - 46). In: The Human Genome: The Book of Essential Knowledge. Watertown, MA: Charlesbridge Publishing. ISBN: 978-1-936140-15-2 **[I have pdf]**

Assignment Due Today:

- Turn in completed forms for: (1) **Genetics Literacy Assessment Instrument (GLAI) for Undergraduates**, (2) **Expanded Numeracy**, and (3) **Subjective Numeracy**.

Between Hilo &Yokohama/Kobe]

Day 3:

- Overview of past to present regarding genetics & genomics and public health: Part I

Reading Assignment:

- Language of Life book: Introduction; Chapter 1; Chapter 2 (pp. 23 – 42)
- On the National Human Genome Research Institute (NHGRI) website, explore the **Section: Issues in Genetics – Policy, Legal, and Ethical Issues in Genetics Research** <http://www.genome.gov/issues/> (Accessed 10/11/12)

Assignment Due Today:

- Before class, submit a list of potential behavioral, social, or ethical issues that you noted while watching the PBS show, "Cracking Your Genetic Code" in a **Word file named: <Genomics and PH_Cracking Code_YOURLASTNAME.doc>**
- Bring to class the list of potential behavioral, social, or ethical issues that you noted while watching the show and be prepared to discuss today.

Day 4:

- Overview of past to present regarding genetics & genomics and public health: Part II

Reading Assignment:

- Zimmern, RL. (2012). The impact of genomics on public health practice: The case for change. Public Health Genomics, 15, 118-124.
- Hudson, KL. (2011). Genomics, health care, and society. New England Journal of Medicine, 365(11), 1033-41.

Assignment Due Today:

None

Day 5:

- Family history
- Genetic counseling and genetic testing

Reading Assignment:

- National Institutes of Health. (2009). NIH State-of-the-Science Conference Statement on Family history and Improving Health. **[I have pdf]**
- National Coalition for Health Professional Education in Genetics. (2007) Core Competencies in Genetics for Health Professionals. **[I have pdf]**

Assignment Due Today:

None

Day 6:

- Genetics and race

Reading Assignment:

- Language of Life book: Chapter 5
- Bonham, V.L. (2010). The role of genetics in understanding racial and ethnic health disparities. J American Academy of Physician Assistants, 23(1), 49-50. **[I have pdf]**

Exemplar: Sickle Cell Testing of College Athletes

- Hord, J.D. & Rice, S.G. (2009). NCAA recommends screening all college athletes for sickle cell trait. AAP News, 30. **[I have pdf]**
- Stein, R. (Sept 10, 2010) Sickle cell testing of athletes stirs discrimination fears. Washington Post. **[I have pdf]**
- Bonham, VL., Dover, GJ, & Brody, LC. (2010). Screening athletes for sickle cell trait – A social and clinical experiment. New England Journal of Medicine, 363(11), 997-99. **[I have pdf]**

Assignment Due Today:

- Complete reading the **first one-third** of your assigned book. As you read, keep a list of behavioral, social, or ethical issues that you note in the book.

- (1) Write a Summary (1-page, single-spaced) of your thoughts and reactions to the **first 1/3** of the book.
- (2) On a second page, list the behavioral, social, or ethical issues that you noted as you read the first 1/3 of book. For each, include their page location. **Submit both in a Word file named: xx.**

Between Yokohama/Kobe & Shanghais/Hong Kong]

Day 7:

- Public understanding of genetics and genomics
- Genetic literacy

Reading Assignment:

- Khoury, MJ. What is Public Health Genomics? A Day in the Invisible Life of Public Health Genomics. <http://blogs.cdc.gov/genomics/2011/06/02/what-is-public-health-genomics-a-day-in-the-invisible-life-of-public-health-genomics/> (Accessed 10/11/12) **[I have pdf]**
- Condit CM. (2010). Public attitudes and beliefs about genetics. Annual Review of Genomics and Human Genetics, 11, 339-59.

OR

- Condit CM. (2010). Public understandings of genetics and health. Clinical Genetics, 77, 1-9.

Assignment Due Today:

None

Between Shanghais/Hong Kong & HCMC]

Day 8:

- Newborn screening

Reading Assignment:

- Language of Life book: Chapter 2 (pp. 42-58)
- Couzin-Frankel, J. (2009). Science gold mine, ethical minefield. Science, 324, 166-168.

Assignment Due Today:

None

Day 9: [[A9 before HCMC; B9 after HCMC]

- Predictive testing for Huntington's disease

Reading Assignment:

- Language of Life book: Chapter 7, (pp. 187-189)
- Wexler, A. (2010). Stigma, history, and Huntington's disease. Lancet, 376(9734), 18-19.
- Explore the Hereditary Disease Foundation website, especially about the work of Nancy Wexler (Alice's sister). <http://www.hdfoundation.org/home.php> (Accessed 10/11/12)

Assignment Due Today:

None

Between HCMC & Singapore/Rangoon

Day 10:

- Susceptibility testing for breast cancer and Alzheimer's disease

Reading Assignment:

Breast Cancer

- Language of Life book: Chapter 4 (pp. 98-134)

Alzheimer's disease

- Language of Life book: Chapter 8 (pp.220-225)
- Arribas-Ayllon M. (2011). The ethics of disclosing genetic diagnosis for Alzheimer's disease: Do we need a new paradigm? British Medical Bulletin, 100, 7-21.

Assignment Due Today:

- Complete reading the **second one-third** of your assigned book. As you read, keep a list of behavioral, social, or ethical issues that you note in the book.
- (1) Write a Summary (1-page, single-spaced) of your thoughts and reactions to the **first 1/3** of the book.
(2) On a second page, list the behavioral, social, or ethical issues that you noted as you read the first 1/3 of book. For each, include their page location. **Submit both in a Word file named: xx.**

Day 11:

- Direct-to-Consumer (DTC) genomic testing

Reading Assignment:

- Language of Life book: Chapter 3
- Spaulding, E.J. (Nov 29, 2011). A closer look. Interpreting risk: Direct-to-Consumer Genetic Testing. NCI Cancer Bulletin, 8(23). <http://www.cancer.gov/ncicancerbulletin/112911/page7> (Accessed 10/11/12)

Assignment Due Today:

None

Between Rangoon & Cochin]

Day 12:

- Gene-environment interactions in complex diseases
- Epigenetics

Watch Epigenetics on Learn Genetics: Genetic Science Univ of Utah website

<http://learn.genetics.utah.edu/content/epigenetics/> (Accessed 10/11/12)

Reading Assignment:

- Childs, B. (2006). Principles of Genetics in the Context of Common Disease, pp. 1-5. Downloaded from NCHPEG website. **[I have pdf]**
- Watch Epigenetics (from scishow) YouTube <http://www.youtube.com/watch?v=kp1bZEUqgVI> (Accessed 10/11/12)

Assignment Due Today:

****Field Lab Assignment from Hong Kong due**

Day 13: [A13 before Cochin; B13 after Cochin]

- Pharmacogenomics

Reading Assignment:

- Language of Life book: Chapter 9
- Nuffield Council on Bioethics. (2006) Pharmacogenetics: Ethical Issues. A Guide to the Report. **[I have pdf]**

Assignment Due Today:

****Turn in first Class Participation Form**

[Between Cochin & Port Louis]

Day 14:

- \$1,000 Genome

Reading Assignment:

- Brown, E. (Jan 10, 2012). What a \$1,000 genome could mean for medicine. Los Angeles Times. **[I have pdf]**
- Hill, C. (Feb 9, 2012) Beyond the \$1,000 genome. Forbes. **[I have pdf]**
- Markoff, J. (March 7, 2012). Cost of gene sequencing falls, raising hopes for medical advances. New York Times. **[I have pdf]**
- Klein, E. (March 8, 2012). How a \$1,000 test could destroy the health-insurance industry. Washington Post. **[I have pdf]**

Assignment Due Today:

None

Day 15:

Assignment Due Today:

Group Presentation – Topic 1: Genetic Research & the Havasupai Tribe

[Between Port Louis & Cape Town]

Day 16:

Assignment Due Today:

Group Presentation – Topic 2: Bi-Dil & Race-Based Medicine

Day 17:

Assignment Due Today:

Group Presentation – Topic 3: Family History as a Tool for Public Health and Primary Care

[
Day 18: [A18 before Cape Town; B18 after Cape Town]

Assignment Due Today:

Group Presentation – Topic 4: Epigenomics & Public Health

[Between Cape Town & Tema]

Day 19:

Checkpoint!!

Assignment Due Today:

****Individual Written Book Review – all Books due**

Day 20:

Assignment Due Today:

Book Group In-Class Oral Summary & Discussion – Books 1 and 2

[Between Tema & Casablanca]

Day 21:

Assignment Due Today:

Book Group In-Class Oral Summary & Discussion – Books 3 and 4

Day 22:

Assignment Due Today:

Book Group In-Class Oral Summary & Discussion – Books 5 and 6

[

Between Casablanca & Barcelona]

Day 23:

Assignment Due Today:

- Book Group In-Class Oral Summary & Discussion – Books 7 and 8
-
- Turn in second completed forms for: (1) **Genetics Literacy Assessment Instrument (GLAI) for Undergraduates**, (2) **Expanded Numeracy**, and (3) **Subjective Numeracy**.
- ****Turn in second Class Participation Form**

FIELD WORK

FIELD LAB (At least 20 percent of the contact hours for each course, to be led by the instructor.)

***Participation is mandatory.**

***20% of your course grade is based on the field assignments drawn from the lab and other in-port experiences.**

Field Lab: Title – Informed Consent and the Family: A Confucian Perspective for China

- Port – Hong Kong
- Date – Final Day Friday 2/08/12
- Destination(s) – City University of Hong Kong
- Number of Projected Participants (maximum class size is 35)
- Duration (hours) of lab – 6 – 8 hours

Academic Objectives:

1. Analyze important social, cultural, and ethical dimensions of genomic discoveries in healthcare and society.
2. Explain ethical principles of informed consent and their applications to genomics and public health.
3. Contextually compare differing ethical perspectives as they relate to genomics and public health ethics.

Field Lab Description:

Professor Ruiping Fan completed medical training in China and a Ph.D. in Philosophy at Rice University. His teaching interests in Hong Kong include: ethics and public policy, social and political philosophy, and health care policy and ethics. (Professor Fan recently visited UVA as a guest of Professor Jim Childress, where he gave a talk and met with faculty and students.)

Students will visit Professor Fan at the City University of Hong Kong, where he will talk with them about the social, cultural, and ethical aspects of informed consent for medical decision making in China from a Confucian perspective. He will lead a discussion with the students to compare the family-oriented Confucian perspective of informed consent to the western self-determined perspective in the U.S. A specific health-related decision-making situation will be addressed, such as genetic testing or genetic enhancement.

METHODS OF EVALUATION / GRADING RUBRIC

TEACHING METHODS:

This course will employ a blend of lecture/discussions, group discussions, multimedia presentations, and written and oral application assignments to explore behavioral, social, and ethical issues as they relate to genomics and public health. Perspectives of different course topics will be enriched by incorporating popular press books in application assignments. Students will also work in small groups to complete selected assignments. Class attendance and participation is expected.

Readiness concept: The responsibility to learn is fundamentally that of the student. In order to succeed in learning, students must actively engage in the process. For this reason, you are expected to come to class prepared. Being prepared means that you will read the assignments, give the assignments thoughtful consideration, and you will be able to advocate for your point of view.

COURSE REQUIREMENTS AND EVALUATION:

1. Readings completed prior to class
2. Class Attendance and Participation [**10 %**] Students are expected to regularly attend class on time and participate actively in class discussions and activities.
3. Individual Written Book Review and Book Group In-class Discussion [**35% total**] Individual Written Book Review [**25%**] and Book Group In-class Oral Summary and Discussion [**10%**] Students will complete an individual written 6-8 page review. All students reviewing the same book will work in a group to (1) prepare and deliver an oral summary and (2) lead an in-class discussion (30 minutes total). Additional guidelines for this assignment are provided later in the syllabus.
4. Group Presentation [**35%**] At the outset of the semester, students will be assigned to groups (size TBD based on course enrollment) to address a course topic. On their assigned week, the group will be responsible for delivering an oral presentation, as well as facilitating classroom discussion of their assigned topic. Additional guidelines for this assignment are provided later in the syllabus.
5. Field Lab [**20%**]

GRADING SCALE for COURSE:

A+= 97-100	B+ =87-89	C+= (77-79)	F = below 70 failing
A= 94-96	B= 84-86	C= 74-76	
A- = 90-93	B- =80-83	C- =70-73	

LATE WORK POLICY:

If you are unable to meet one or more of the deadlines in this course, please contact me to negotiate a different due date. I usually grant reasonable requests made **well before** the due date (48 hours or more). Unless an extension is granted, I will not accept late work.

GENOMICS AND PUBLIC HEALTH: CRITERIA FOR EVALUATING CLASS PARTICIPATION

10% of Grade

CLASS PARTICIPATION FORM

Student:

Date:

This self-evaluation will be used to assess your overall class participation at **middle** and **end of the course**. Any additional information that you would like me to consider in determining your grade should be included in the Comment section below.

Directions: Rate each item: Always (5) -- Rarely (1) by recording number in the right hand column.

1. Attends class and responds to study questions and class discussion.	
2. Prepares for class – Reading and preparation assignments done prior to class.	
3. Actively and thoughtfully contributes to discussions -- Substantively responds to classmates' comments.	
4. Utilizes active listening skills to foster discussion.	
5. Incorporates content from readings into class discussions.	
6. Respects the contributions and opinions of others.	
7. Raises appropriate issues and questions to facilitate discussion.	
Comments:	

Genomics and Public Health: Behavioral, Social, and Ethical Issues

Book Review ASSIGNMENT

Individual Written Book Review [25%] and Book Group In-Class Summary and Discussion [10%] of a popular press book focused on course topics

- Students will complete an individual written 8-10 page review.
- All students reviewing the same book will work in a group to (1) prepare and deliver an oral summary and (2) lead an in-class discussion (30 minutes total).

Individual Written Book Review Assignment due Day 19.

In-Class Summary and Discussion due – TBD by book.

Individual Written Book Review Assignment Information [25%]

Purpose of the Assignment

The goals of this assignment include: (1) allowing you to explore a course topic in greater detail; (2) application of critical thinking skills to the field of genomics and public health – its behavioral, social, and ethical aspects; and (3) developing the ability to produce effective written and oral summaries and evaluations of course-related topics and materials.

Selecting a Book for Your Review

Students (**number per book TBD** based on course enrollment) will be **assigned at the beginning of the semester to one of the books** below:

1. Misha Angrist – Here Is a Human Being: At the Dawn of Personal Genetics (2010)
2. Levin Davies – The \$1,000k Genome: The Revolution in DNA Sequencing and the New Era of Personalized Medicine (2010)
3. George Estreich – The Shape of the Eyes: Down Syndrome, Family, and the Stories We Inherit (2011)
4. Lone Frank – My Beautiful Genome: Exposing Our Genetic Future, One Quirk At a Time (2011)
5. Thomas Goetz – The Decision Tree: Taking control of Your Health in the New Era of Personalize Medicine (2010)
6. Jessica Queller – Pretty Is What Changes (2009)
7. Rebecca Skloot – The Immortal Life of Henrietta Lacks (2011)
8. Alice Wexler – The Woman Who Walked into the Sea: Huntington's and the Making of Genetic Disease (2010)

Students may not suggest alternate books for this assignment.

Components of the Individual Written Book Review

The review should include the following sections and be labeled/organized accordingly:

Introduction. The review should briefly identify the book and place it in the larger context of the genomics and public health issues it raises. Also briefly discuss the author, including his/her background as it relates to the topic. **[10%]**

Summary. The review should concisely summarize the main points of the book -- detailing its major themes, methodologies, and arguments or findings. **[20%]**

Discussion of genomics and public health themes. The review should discuss how the book addresses genomics and public health -- behavioral, social, and/or ethical issues -- in class topics, readings, and discussions. **[60%]**

Critical evaluation. The review should offer a brief critique of the strengths and limitations of the book, based upon what you have learned from class and a consideration of the broader literature in the field. **[10%]**

Here are some questions you might consider in your evaluation:

- Is the book a compelling and provocative read?
- Does it promote greater awareness and understanding of the issues at hand?
- Is the author a credible expert on the material?
- Is the book hampered by particular biases?
- Are conclusions fully supported by available evidence?

Other Information

Length. The review should be **8 - 10 pages (double-spaced)** in length, **not including title page or references.**

References. Although you are not expected to conduct a formal literature review for this assignment, your review should include citation of course readings and/or additional references that inform your discussion and support your report. These should be included in a formal References section.

Grading. This assignment will be graded according to how well it addresses the four components listed above, with clarity and organization of content also factored into the evaluation.

Book Group In-Class Oral Summary & Discussion Information **[10%]**

All students reviewing the same book will work in a group to: (1) prepare and deliver a brief oral summary and (2) lead an in-class discussion with the class (30 minutes total).

Genomics and Public Health: Behavioral, Social, and Ethical Issues

In-Class Group Presentation ASSIGNMENT

35% of Grade

Overview

At the outset of the course, each student will be assigned to a small group (**size TBD** based on course enrollment) that will lead a one-hour session on the assigned topic for that week. The group will be responsible for a **formal oral presentation** on the topic, as well as for facilitating class discussion during and/or after the presentation. (Note: The entire class will be assigned an article briefly familiarizing them with the session topic.) **The main goals of the assignment** are for students to (1) enhance their knowledge of a course-related topic of interest; (2) develop genomics and public health knowledge, oral presentation skills, and discussion facilitation skills; and (3) gain experience in working in groups.

Assignment Components

1) Oral presentation. The group should draw upon credible outside resources (e.g., relevant scientific literature, educational websites, media coverage) to provide background on the assigned topic. Group members should collaborate to produce a slide show presentation using Power Point for the class. **Each member should present a part of the presentation – everybody speaks!**

Questions to consider in developing your presentation may include the following:

- How does this topic relate to broader behavioral, social, and ethical themes for genomics and public health considered in the course (e.g., what ELSI issues does it raise)?
- Who are the major stakeholders involved?
- What needs related to health and health care are prompted by this topic, and how are they currently being met (or not)?

2) Group discussion. During and/or following the formal oral presentation, the group should engage the class in discussion of issues raised in their presentation. The group should develop **written questions and a plan of action to guide group discussion** (e.g., breaking down into small groups, development of vignettes to stimulate consideration of particular issues). For more information about designing group discussion activities, see this section of the Center for Research on Learning & Teaching website at the University of Michigan: <http://www.crlt.umich.edu/tstrategies/tsd> (Accessed 10/11/12)

Grading

This assignment counts for **35% of the overall course grade**. The group will also receive written feedback from classmates (see peer feedback form). The **following materials are due on the day of the presentation** (submit electronically to the instructor), and they will be posted to the course website as resources for your fellow students.

- **Power Point slides** and/or other materials used in the oral presentation. Remember to provide references on your slides as appropriate.
- An **annotated brief bibliography** (at least 8-10 citations, with 2- to 3-sentence description for each) of further readings and resources on the topic of interest
- A **discussion guide** (1-2 pages) consisting of questions and/or activities to facilitate group discussion.

Peer Evaluations (see forms in “Group Presentations”)

Students in the audience will complete peer evaluation forms that will be collected at end of class and provided to the group at the following class session. Although these evaluations will not be factored into grading, they should provide a valuable complement to instructor feedback. In addition, you will complete a within-group peer

evaluation to rate the performance of group members, including yourself. This exercise should enhance accountability to others, and group members may receive different grades for the assignment if these evaluations (coupled with the instructor's observations) suggest significantly unequal contributions to the assignment.

Helpful Hints

Plan ahead. This sounds obvious, but prior groups have been hampered by an inability to meet early and often enough to devote adequate time to researching the topic, dividing up responsibilities, brainstorming discussion ideas, and practicing your talks. Group members are often stretched thin across numerous commitments and conflicting schedules, so it will pay off to get your planning process started early. Also, I highly encourage you to meet with me at least a week before the presentation to discuss your plan for the group presentation. I will be able to provide strategic feedback on your approach to the topic.

Consider a pre-session activity. To prime your fellow students for your session, you might engage them ahead of your presentation. You could ask students to read through your discussion exercise prior to class. In this manner, you can get them thinking about your topic beforehand so that they come to class better prepared to participate actively in discussion.

Practice makes perfect. A formal "dress rehearsal" should be an indispensable part of your preparation. This will allow you to more fully master content, improve the flow and transitions across different segments of the presentation, and ensure you have an appropriate amount of materials to cover (time limits will be strictly enforced). You will also be more likely to catch flaws in your slides and to generate helpful feedback on your respective presentation styles.

Speaking style. You don't have to be a master orator to avoid the problems of some prior group presentations. For example, don't chew gum during your talk. Look at the audience and not back at the screen the whole time. Speak so that everyone can hear you and avoid a completely monotone delivery. Again, sounds obvious, but these things have happened on multiple past instances (okay, only one person ever chewed gum throughout her talk).

Manage time wisely. An hour may seem like a long time, but you will be surprised how quickly it goes. Some prior groups have not been able to get through all their planned materials and/or have had to rush through closing exercises. There are several things to keep in mind as you plan your presentation. You probably don't want more than 25-30 slides in your formal Power Point slideshow, and a crisp, well-rehearsed delivery of these will also aid time management. In addition, you should be prepared to moderate or close down early discussions to ensure adequate time for all sections of your presentation.

Brief Descriptions of Group Presentation Topics

Genetic Research with the Havasupai tribe

The Havasupai Indian tribe in the Grand Canyon recently won a large settlement from Arizona State University for misconduct in genetic research conducted with its members. Tribe members felt deceived about the research they had consented to and objected to some of the conclusions of research findings (e.g., regarding ancestral origins of the tribe and risk of schizophrenia). The case illustrates numerous ethical tensions involved in genetic research with minority populations; this group will provide background on the case and discuss issues of public trust, informed consent, and ownership rights regarding biological / genetic research samples.

Bi-Dil and Race-Based Medicine

In 2005, the FDA approved the medication Bi-Dil to treat congestive heart failure in African American patients only. Proponents, including the Association of Black Cardiologists, claimed it represented a breakthrough treatment that could help address health disparities in heart disease. However, many commentators criticized the decision as unwisely reinforcing the notion of race as a biological construct and questioned the drug maker's motives in seeking a patent on this "race-based" medicine. This group will describe the Bi-Dil case and address larger ethical and social issues it raises about the use of race in medicine and genetic research.

Family History as a Tool for Public Health and Primary Care

Family history has long been recognized as a useful means of identifying high-risk groups for a host of diseases. From a public health standpoint, it represents a potentially lower cost alternative to high-tech genetic testing options. This group will review the importance of family history as a risk factor and its continuing importance for common diseases, despite recent genomic advances. Describe efforts in the U.S. (e.g., Surgeon General's Family Health History Tool) to enhance the collection and use of family history by both health professionals and the general public. Challenges from incorporating family history into electronic health records (EHR) will be identified. Issues related to sharing family history information among family members will be described.

Epigenetics and Public Health

The rapidly emerging field of epigenetics addresses heritable changes in gene activity distinct from the underlying DNA sequence. The field is of particular interest to public health because it could help explain how environmental and health behavior factors like stress, diet, and smoking can affect gene expression in ways that are passed down to the next generation. This group will provide an overview of the field that is accessible to the educated layperson and discuss ways in which epigenomics might inform understanding of complex health conditions, as well as future health promotion efforts.

Preferences for Group Presentation Topics

Instructions

Below are the proposed topics for the Group Presentation Assignment. Please indicate your preferences by rank-ordering them from 1 to 5 (1 = most interested to 5 = least interested). Make sure to rate each item.

If there is anything the instructor should know when making group assignments (e.g., scheduling conflicts with particular dates), please indicate in the **Comments** section. You can also use this section to elaborate on your reasons for interest in your highest rated topics.

Your name:

Topics

- _____ Genetic Research with the Havasupai Tribe – Day 15
- _____ The Bi-Dil Case and Race-based Medicine – Day 16
- _____ Family History as a Tool for Public Health & Primary Care – Day 17
- _____ Epigenetics and Public Health – Day 18

Student Comments

RESERVE LIBRARY LIST

[NOTE: Two copies of these eight books are required for the semester-long Individual Written Book Review and Book Group In-class Summary and Discussion Assignment. Students may need to be able to sign them out for more than two hours.]

AUTHOR: Misha Angrist
TITLE: Here Is a Human Being: At the Dawn of Personal Genetics
PUBLISHER: Harper
ISBN #: 0061628336
DATE/EDITION: 2010

AUTHOR: Levin Davies
TITLE: The \$1,000k Genome: The Revolution in DNA Sequencing and the New Era of Personalized Medicine
PUBLISHER: Free press
ISBN #: 1416569596
DATE/EDITION: 2010

AUTHOR: George Estreich
TITLE: The Shape of the Eyes: Down Syndrome, Family, and the Stories We Inherit
PUBLISHER: Southern Methodist University Press
ISBN #:0870745670
DATE/EDITION: 2011

AUTHOR: Lone Frank
TITLE: My Beautiful Genome: Exposing Our Genetic Future, One Quirk at a Time
PUBLISHER: Oneworld
ISBN #:1851688331
DATE/EDITION: 2011

AUTHOR: Thomas Goetz
TITLE: The Decision Tree: Taking control of Your Health in the New Era of Personalize Medicine
PUBLISHER: Rodale Books
ISBN #:1605297291
DATE/EDITION: 2010

AUTHOR: Jessica Queller
TITLE: Pretty Is What Changes
PUBLISHER: Spiegel & Grau
ISBN #:0385520417
DATE/EDITION: 2009

AUTHOR: Rebecca Skloot
TITLE: The Immortal Life of Henrietta Lacks
PUBLISHER: Broadway
ISBN #:1400052181
DATE/EDITION: 2011

AUTHOR: Alice Wexler
TITLE: The Woman Who Walked into the Sea: Huntington's and the Making of Genetic Disease
PUBLISHER: Yale University Press
ISBN #:0300158610
DATE/EDITION: 2010

ELECTRONIC COURSE MATERIALS

AUTHOR: Quackenbush, J
CHAPTER TITLE: Chapter 1: Back to Basics
BOOK TITLE: The Human Genome: The Book of Essential Knowledge [ISBN: 978-1-936140-15-2]
VOLUME: N/A
DATE: 2011/1st ed
PAGES: 21-46

AUTHOR: Zimmern, RL
ARTICLE/CHAPTER TITLE: The impact of genomics on public health practice: The case for change
JOURNAL/BOOK TITLE: Public Health Genomics
VOLUME: 15
DATE: online April 4, 2012
PAGES: 118-124

AUTHOR: Hudson, KL
ARTICLE/CHAPTER TITLE: Genomics, health care, and society
JOURNAL/BOOK TITLE: New England Journal of Medicine
VOLUME: 365(11)
DATE: Sept, 2011
PAGES: 1033-41.

AUTHOR: National Institutes of Health
ARTICLE/CHAPTER TITLE: NIH State-of-the-Science Conference Statement on Family history and Improving Health
JOURNAL/BOOK TITLE: National Institutes of Health
VOLUME: 26 (1)
DATE: Aug, 2009
PAGES: 1-31

AUTHOR: National Coalition for Health Professional Education in Genetics
ARTICLE/CHAPTER TITLE: Core Competencies in Genetics for Health Professionals
JOURNAL/BOOK TITLE:
VOLUME:
DATE: Sept, 2007
PAGES:

AUTHOR: Bonham, V.L.
ARTICLE/CHAPTER TITLE: The role of genetics in understanding racial and ethnic health disparities.
JOURNAL/BOOK TITLE: J American Academy of Physician Assistants
VOLUME: 23(1)
DATE: Jan, 2010
PAGES: 49-50

AUTHOR: Hord, J.D. & Rice, S.G.
ARTICLE/CHAPTER TITLE: NCAA recommends screening all college athletes for sickle cell trait.
JOURNAL/BOOK TITLE: AAP News
VOLUME: 30
DATE: 2009
PAGES:

AUTHOR: Stein, R.
ARTICLE/CHAPTER TITLE: Sickle cell testing of athletes stirs discrimination fears
JOURNAL/BOOK TITLE: Washington Post
VOLUME:

DATE: Sept 10, 2010

PAGES:

AUTHOR: Bonham, VL., Dover, GJ, & Brody, LC.

ARTICLE/CHAPTER TITLE: Screening athletes for sickle cell trait – A social and clinical experiment

JOURNAL/BOOK TITLE: New England Journal of Medicine

VOLUME: 363(11)

DATE: 2010

PAGES: 997-99

AUTHOR: Khoury, Muin J.

ARTICLE/CHAPTER TITLE: What is Public Health Genomics? A Day in the Invisible Life of Public Health Genomics

JOURNAL/BOOK TITLE: Genomics and Health Impact Blog (CDC.gov)

DATE: June 2nd, 2011

SITE: <http://blogs.cdc.gov/genomics/2011/06/02/what-is-public-health-genomics-a-day-in-the-invisible-life-of-public-health-genomics/> (Accessed 10/11/12)

AUTHOR: Condit CM.

ARTICLE/CHAPTER TITLE: Public attitudes and beliefs about genetics

JOURNAL/BOOK TITLE: Annual Review of Genomics and Human Genetics

VOLUME: 11

DATE: 2010

PAGES: 339-59

AUTHOR: Condit CM.

ARTICLE/CHAPTER TITLE: Public understandings of genetics and health

JOURNAL/BOOK TITLE: Clinical Genetics

VOLUME: 77

DATE: 2010

PAGES: 1-9

AUTHOR: Couzin-Frankel, J.

ARTICLE/CHAPTER TITLE: Science gold mine, ethical minefield

JOURNAL/BOOK TITLE: Science

VOLUME: 324

DATE: 2009

PAGES: 166-168

AUTHOR: Wexler, A.

ARTICLE/CHAPTER TITLE: Stigma, history, and Huntington's disease

JOURNAL/BOOK TITLE: Lancet

VOLUME: 376(9734)

DATE: 2010

PAGES: 18-19

AUTHOR: Arribas-Ayllon M.

ARTICLE/CHAPTER TITLE: The ethics of disclosing genetic diagnosis for Alzheimer's disease: Do we need a new paradigm?

JOURNAL/BOOK TITLE: British Medical Bulletin

VOLUME: 100

DATE: 2011

PAGES: 7-21

AUTHOR: Spaulding, EJ.

ARTICLE/CHAPTER TITLE: A closer look. Interpreting risk: Direct-to-Consumer Genetic Testing.
JOURNAL/BOOK TITLE: NCI Cancer Bulletin
VOLUME: 8(23)
DATE: Nov 29, 2011
SITE: <http://www.cancer.gov/ncicancerbulletin/112911/page7> (Accessed 10/11/12)

AUTHOR: Woolshin, S.
ARTICLE/CHAPTER TITLE: Promoting Healthy Skepticism in the News: Helping Journalists Get It Right
JOURNAL/BOOK TITLE: Journal of the National Cancer Institute
VOLUME: 101(23)
DATE: Dec, 2009
PAGES: 1596-1599

AUTHOR: Nuffield Council on Bioethics.
ARTICLE/CHAPTER TITLE: Pharmacogenetics: Ethical Issues. A Guide to the Report.
JOURNAL/BOOK TITLE: Nuffield Council on Bioethics.
VOLUME:
DATE: 2006
PAGES: 1-7

AUTHOR: Brown, E.
ARTICLE/CHAPTER TITLE: What a \$1,000 genome could mean for medicine
JOURNAL/BOOK TITLE: Los Angeles Times
VOLUME:
DATE: Jan 10, 2012
PAGES: 1

AUTHOR: Hill, C.
ARTICLE/CHAPTER TITLE: Beyond the \$1,000 genome
JOURNAL/BOOK TITLE: Forbes
VOLUME:
DATE: Feb 9, 2012
PAGES: 1-2

AUTHOR: Markoff, J.
ARTICLE/CHAPTER TITLE: Cost of gene sequencing falls, raising hopes for medical advances.
JOURNAL/BOOK TITLE: New York Times
VOLUME:
DATE: March 7, 2012
PAGES: 1-4

AUTHOR: Klein, E.
ARTICLE/CHAPTER TITLE: How a \$1,000 test could destroy the health-insurance industry
JOURNAL/BOOK TITLE: Washington Post
VOLUME:
DATE: March 8, 2012
PAGES: 1-2

ADDITIONAL RESOURCES

None

HONOR CODE

Semester at Sea students enroll in an academic program administered by the University of Virginia, and thus bind themselves to the University's honor code. The code prohibits all acts of lying, cheating, and stealing. Please consult the Voyager's Handbook for further explanation of what constitutes an honor offense.

Each written assignment for this course must be pledged by the student as follows: "On my honor as a student, I pledge that I have neither given nor received aid on this assignment." The pledge must be signed, or, in the case of an electronic file, signed "[signed]."

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