

Bioethics (Fall 2012)  
Professor Ikemoto  
UC Davis Law School  
Henrietta Lacks & HeLa

Teaching module provided by Dr. Katayoun Chamany, Assoc. Prof. of Biology, Eugene Lang College,  
The New School.

Please do not distribute to others. This is a Beta-test module being developed for the National Center  
for Case Study Teaching in Science.

## Syllabus Follows

### Stakehold Perspective Assignment

**Choose one:**

David Lacks Jr., Kimberley Lacks

- 1)
- 2)

George and Margaret Gey

- 1)
- 2)

Richard Wesley TeLinde

- 1)
- 2)

Edward Panelli (see *Moore*)

- 1)
- 2)

Stanley Mosk (see *Moore*)

- 1)
- 2)

William Catalona and his patients

- 1)
- 2)

Rebecca Skloot

- 1)
- 2)

**Review** the readings and research biographical information about your stakeholder.

### **Ms. Henrietta Lacks & HeLa in Context**

1. Rebecca Skloot, *The Immortal Life of Henrietta Lacks* 9, 13-33 (2010).
2. Curtis, 1997. *Modern Times: The Way of All Flesh*. Aired on BBC. Modern Times Series, Editor Stephen Lambert. 52 minutes. <http://tenpercent.wordpress.com/2009/02/08/adam-curtis-the-way-of-all-flesh/>
3. Hannah Landecker, *The HeLa Stories*, in *Culturing Life* 162-179 (2007).

### **Research Ethics**

1. Ehrlich, R. (1997). *In Memory of Henrietta Lacks*. Congressional Record. <http://0-www.gpo.gov.library.colby.edu/fdsys/pkg/CREC-1997-06-04/pdf/CREC-1997-06-04-pt1-PgE1109.pdf>
2. Perriello T. May 28, 2010. *Honoring Henrietta Lacks*. Congressional Record. <http://www.gpo.gov/fdsys/pkg/CREC-2010-05-28/pdf/CREC-2010-05-28-pt1-PgE1008-3.pdf>
3. Erin Biba, *Henrietta Everlasting: 1950s Cells Still Alive, Helping Science*. *Wired Magazine* (Feb. 2010). [http://www.wired.com/magazine/2010/01/st\\_henrietta/](http://www.wired.com/magazine/2010/01/st_henrietta/)
4. Dale Keiger, *Immortal Cells, Enduring Issues*, *John Hopkins Magazine* 1-6 (June 2, 2010). <http://archive.magazine.jhu.edu/2010/06/immortal-cells-enduring-issues/>
5. Amy Harmon, *Indian Tribe Wins Fight to Limit Research of Its DNA*, *NY Times*, April 21, 2010. <http://www.nytimes.com/2010/04/22/us/22dna.html?pagewanted=all&r=0>
6. Michelle Mello & Leslie E. Wolf, *The Havasupai Tribe Case – Lessons for Research Involving Stored Biologic Samples*, *363 NEJM* 204-207 (July 15, 2010). <http://www.nejm.org/doi/full/10.1056/NEJMp1005203?query=current&rss=1>

### **Commodification**

1. Rebecca Skloot, *Taking the Least of You*, *N.Y. Times Magazine*, April 16, 2006. <http://www.nytimes.com/2006/04/16/magazine/16tissue.html?pagewanted=all&r=0>
2. Patricia Cohen, *Returning the Blessing of an Immortal Life*. *N.Y. Times*, Feb. 5, 2011, C1. <http://www.nytimes.com/2011/02/05/books/05lacks.html>
3. Lynn G. Dressler, *Biospecimen “Ownership”*: Counterpoint, *16 Cancer Epidemiol. Biomarkers* 190-191 (Feb. 14, 2007). <http://cebp.aacrjournals.org/content/16/2/190.full.pdf+html>

### **Prepare** (for discussion)

- 1) To make a brief statement about your stakeholder – who is she or he?
- 2) Answer questions from your stakeholder’s perspective, including:
  - Was Henrietta Lacks wronged? If so, how? If no, why not?
  - Should consent to use of her tissue have been obtained?
  - Should Henrietta Lacks and her family have been informed of the use of her cells? If so, when/at what stage?
  - Should she have had a property interest or a claim other than breach of fiduciary duty?

## **Syllabus**

### **Time and Place**

**Class meetings:** Mondays, Wednesdays & Thursdays, 11:00 – 11:50 a.m.,  
Room 2320

**NOTE:** Class will not meet on Wednesday, November 28 and Thursday, November 29. Make-up times will be scheduled earlier in the semester.

**Office**

Room 2115

Telephone: 530/754-6463

Email: [lcikemoto@ucdavis.edu](mailto:lcikemoto@ucdavis.edu)

**Reading Materials**

Dolgin & Shepherd, *Bioethics and the Law* (2d ed. 2009)

Other materials will be distributed in class or assigned on-line.

**Basic Requirements – Summary**

Regular class attendance, completion of reading assignments, regular and thoughtful participation in class discussion.

*NOTE: Failure to participate on a regular basis can negatively affect your grade. Failure to attend class on a regular basis will result in disenrollment in the course.*

Completion of writing assignments (described below), including 20-page research paper.

*NOTE: Failure to turn in assignments, including failure to turn in assignments on-time will negatively affect your grade.*

Work-in-Progress commentary and presentation (described below).

*NOTE: Failure to provide assigned commentary or a presentation will negatively affect your grade.*

**WRITING ASSIGNMENTS**

**Research Paper Topic:** Due THURSDAY, SEPTEMBER 6, at the beginning of class.

You must meet with Professor Ikemoto and receive pre-approval of your topic before September 6.

On Thursday, September 6, please turn in a short (1-3 sentences) description of your paper topic.

**Research Paper Outline:** Due THURSDAY, September 27, at the beginning of class.

2-5 pages in writing – must include major headings, sub-headings, and a one paragraph description of each major section of the paper; and a preliminary thesis statement.

**Case Study:** The Case Study assignment will be part of the unit on Issues in Emerging Genetic Technologies. Materials and instructions for the Case Study will be distributed

**Research Paper – Draft:** Due ONE WEEK BEFORE your Work-in-Progress Presentation. Work-in-Progress Presentations will take place from mid-November to November 26.

**Works-in-Progress Comments:** You will have primary responsibility for providing written and oral comments on two works-in-progress by classmates. Your comments will be due in class when the relevant work-in-progress is presented. Criteria for comments distributed in class in mid-semester.

**Research Paper – Final Paper:** Due THURSDAY, DECEMBER 20 by NOON.

You may deliver a hard copy to me in my office or my mailbox, or you may email a copy to me at [lcikemoto@ucdavis.edu](mailto:lcikemoto@ucdavis.edu) Only the final paper will be given a letter grade. The other assignments will be graded on a Satisfactory/Unsatisfactory basis. Missing a due date or turning in an assignment that receives an “Unsatisfactory” will negatively affect your course grade by half a grade.

**WORKS-IN-PROGRESS ASSIGNMENTS**

Each student will present her/his paper in a work-in-progress session during the last 2-3 weeks of class. Each paper will receive a 20 minute session. During that session, the author will make a 5 minute presentation of the draft paper; two assigned commenters will provide constructive commentary on the draft; the rest of the class will then participate in a discussion of the draft.

The author must distribute the draft one week before the scheduled work-in-progress session. Assigned commenters must provide written, as well as, oral comments. The Works-in-Progress Schedule will be set up mid-semester

## READING ASSIGNMENTS

All pages below refer to the Dolgin & Shepherd text unless otherwise indicated.

- I. Introduction to bioethics
  - A. "Bioethics" 3-12, Moreno, Stolberg
  - B. The Human Body, Health and Disease 38-42, Fee & Krieger, Peace
  - C. Biomedicalization Clarke et al.
- II. Autonomy and Bodily Integrity
  - A. Informed Consent – Doctrinal analysis 45-68
  - B. Critique of dominant framework Fisher, Lombardo, Fritz, *Moore* & Ram
- III. Human Subject Research
  - A. History, Bioethical and Social Perspectives 401-411
  - B. Regulation <http://ohsr.od.nih.gov/index.html>  
>> Regulations and Ethical Guidelines
    - Nuremberg Code
    - World Medical Association Declaration of Helsinki
    - 45 CFR 46
    - Guidelines for Conduct of Research Involving Human Subjects at NIH 434-447, including *Greenberg*
  - C. Current Practices and Recent Issues 411-423
  - D. Special Populations 449-451, Handout
  - E. Guinea-Pigging Elliott
- IV. Assisted Reproductive Technology Use & Reprogenetics
  - A. Introduction 161-167
  - B. The Technologies 167-172  
Browse: <http://www.ucsfivf.org/ucsf-services.htm>
  - C. The Industry Spar
  - D. Surrogacy 172-189,
  - E. Embryos 189-196  
129-136
  - F. Gamete procurement Handout
  - G. Reprogenetics & Other Selection Issues 338-351,  
223-235, Handout
- V.. Issues in Emerging Genetic Technologies Handout
  - A. Introduction
  - B. HeLa Case Study
  - C. Stem Cell Research & Regenerative Medicine
  - D. Direct to Consumer Genetics
  - E. Synthetic Biology

VI. Selected End of Life Issues

- A. Introduction 735-737
- B. Definitions and Determinations of Death 837-851
- C. Withholding or Terminating Life-Sustaining Treatment
  - 1. Patients without Competency 738-765, 72-75, Miles & August
  - 2. Competent Patients Who Wish to Refuse Treatment 83-88, 776-793, Handout, Re-read
  - 3. When the Patient or Her Family Wants "Futile" Treatment 793-800
- D. Physician Aid in Hastening Death 800-836, Peace

VII. Works-in-Progress