

Research Topics related to “The Immortal Life of Henrietta Lacks”

John Hopkins Hospital

Use this site as a starting point for research: <http://fyb.umd.edu/HeLa/hopkins.html>

1. What is the mission of the hospital? How did it differ from other hospitals? Was this truly revolutionary for the time? How so?
2. Does John Hopkins have a good reputation for medical treatment of patients in the past and in the present? What does a good reputation mean? Advances in treatments, excellent bed manner, equal treatment for all?

HeLa cells

1. How would you define the HeLa cells collected from Henrietta Lacks? How would you define the cells today? Why?
2. What is the connection between HeLa cells and Polio and Sickle Cell? Look for other current experiments using HeLa or dealing with contamination of HeLa. Is the line currently a help or a hindrance to scientific advances? Explain

Tuskegee

1. “For forty years between 1932 and 1972, the U.S. Public Health Service (PHS) conducted an experiment on 399 black men in the late stages of syphilis. These men, for the most part illiterate sharecroppers from one of the poorest counties in Alabama, were never told what disease they were suffering from or of its seriousness. Informed that they were being treated for “bad blood,” their doctors had no intention of curing them of syphilis at all. The data for the experiment was to be collected from autopsies of the men, and they were thus deliberately left to degenerate under the ravages of tertiary syphilis—which can include tumors, heart disease, paralysis, blindness, insanity, and death. “As I see it,” one of the doctors involved explained, “we have no further interest in these patients until they die.”

Describe the Tuskegee Experiment. Were there benefits to the experiment and ramifications we see in the present day?

2. Are there new laws in place to ensure the Tuskegee experiments are not repeated? Is science stifled by regulations? Is there a possibility for similar experimental programs to be run currently based not on race but on socioeconomics? Is this a reality with which the scientific community can take advantage of to further gains in science for the greater good? Does the means justify the ends?
3. Read the Nuremberg Code. <http://ohsr.od.nih.gov/guidelines/nuremberg.html> Then google the code and do some research about the code. Is this applicable in today’s modern medical environment or does it need revising. Explain. What improvements would you suggest and why?
4. Define in your own words the term Informed consent. Is the Helsinki document needed in addition to the Nuremberg Code? Why or why not? Does it allow too much freedom to practitioners? Does it allow for more gains by the scientific community than under the Nuremberg Code?
5. What does GINA stand for? Do you think this act protects Americans from discrimination in the present medical climate? Is there a real threat for discrimination? Do you have any evidence to support this? Think of the movie GATTACCA from Biology. Do you think this is a real possibility? Should we be screening people for medical risks? Why? What are the benefits and cons? Can we find a fair middle ground? Explain.

GINA: Legislative History (National Human Genome Research Institute)

The President has signed into law the Genetic Information Nondiscrimination Act (GINA) that will protect Americans against discrimination based on their genetic information when it comes to health insurance and employment. The bill had passed the Senate unanimously and the House by a vote of 414 to 1. The long-awaited measure, which has been debated in Congress for 13 years, will pave the way for people to take full advantage of the promise of personalized medicine without fear of discrimination.

6. Who were the Night Riders? Read this link to get one point of view about the evolving relationship between medicine and race/socioeconomic barriers. What are your thoughts about current American Medical practice? Is medicine equal for all citizens? Explain. Should it be or not? Explain.

[Renewing Trust in Regular \(Allopathic\) Medicine and Research](#) (Selam International) Spring 2007.

In US academic health centers, inequality reigns at many levels. At the physician level after one and a half

centuries of trying, females are entering medical schools at comparable or higher percentages than males. However, males still predominate in academic health center positions of upper administration and as senior faculty. At the patient level, inequities exist in the recipients of services. Some racial and ethnic groups are highly underrepresented in the patient population, not only as recipients of health services but also as the focus of research. The purpose of this article is to uncover some of the history leading to racial inequities in patient populations, to extend the discussion to inequities in advancement opportunities for women in academic health and to provide suggestions for improvement.

7. Choose one or more of the following cases or instances and become more familiar with the circumstances. Record your reflections and be prepared to discuss in class with notes.

- Mississippi Appendectomy
- Havasupei case: Read through some of the links and explain what the university's goal of the trial was? Did this trial compromise patient rights? If yes, How so?

Research Without Patient Consent (Who Owns Your Body) 2007.

Can scientists do genetic research on your tissues without your consent? That's the essential question in a lawsuit pending before Judge Janet E. Barton of the Maricopa County Superior Court in Arizona. Members of the Havasupai Tribe allege that researchers from Arizona State University (ASU) and the University of Arizona collected 400 blood samples from tribal members for diabetes research, but that those same samples were used for additional unauthorized research on schizophrenia, inbreeding, and population migration. The tribe asserts that research on schizophrenia and inbreeding stigmatizes them and that they would not have authorized any migration research because it conflicts with their religious origin story.

- Define Herd Immunity in relation to Vaccines. Due to the recent wave of parents refusing to immunize their children, there is a resurgence of diseases such as Whooping cough. Does the government have a fundamental responsibility to ensure the health of all its citizens by enforcing vaccines? Explain Cite some evidence to back your stand.
- John Moore and Hairy Cell Leukemia
- Joseph Mengele and Dr. Giselle Perle: Look through the links and read the following article. Did Dr. Giselle act as a humanitarian in her time in the prison camp?
 - **Out of Death, a Zest For Life** (The New York Times) 1982. Every time Dr. Gisella Perl enters a delivery room, she stops first to pray: "God, you owe me a life, a living baby." That debt was incurred in Auschwitz in World War II, when the Hungarian gynecologist, who was both inmate and physician at the concentration camp, realized that to save the lives of hundreds of pregnant women, she would have to prevent them from giving birth.
- CIA Vaccine Ruse
 - It has been reported that in order to locate Osama bin Laden, public health officials started a Hepatitis B vaccine program, extracting DNA from children. The CIA has been accused of using this vaccine program to find bin Laden's children and in turn, find him. The danger of a program like this is that the public would become suspicious of immunization programs in the future.

8. Research the Prometheus Case and the ACLU case on BRCA patents? Start with google and key words gene patent lawsuits.

<http://www.aclu.org/free-speech-womens-rights/aclu-challenges-patents-breast-cancer-genes-0>

After you look at some articles, what are your feelings about patenting genes? Is this a potential threat to gaining more scientific knowledge? What are some pros and cons in favor of patents? What do you predict will be the outcome in the next few years and resulting change in the medical field?

These questions are a compilation from various book group sites as well as the author's and myself. <http://rebeccasklout.com/>. The purpose of this list is to create a constructive platform for discussions between students and their parents and each other. Feel free to deviate from these prescribed questions and to add your own thoughts for discussion. Students and parents alike should be journaling through their reading. Journal entries may be typed or hand written. The first reading assignment is to read the story from two different points of view.

1. What social and/or economical implications are presented?
2. What are the scientific and ethical implications?

Record your part of the discussion at home with regards to these questions. Students and parents alike may also enter reflections, thoughts and ideas on the blog: <http://phsanatomy.pusd.wikispaces.net/> . Journal entries will be checked for completeness.

1. What does this book tell us about the history of science and how science has progressed from the 1950s? After reading this book and considering the events it details, what do you think are key factors that influence scientific progress?
2. The book is filled with stories of people used as research subjects, sometimes without their knowledge, sometimes with ill-informed consent, sometimes because of their inability to understand (patients with mental illness) or resist (prisoners). Were you aware of this history before reading the book? Do you think doctors and researchers of the past had a fundamentally different view of people that they do today? Explain.
3. The passage in which the initial fated cells were removed from Henrietta Lacks's body reads as follows (see page 33):

“With Henrietta unconscious on the operating table in the center of the room, her feet in stirrups, the surgeon on duty, Dr. Lawrence Wharton, Jr., sat on a stool between her legs. He peered inside Henrietta, dilated her cervix, and prepared to treat her tumor. But first – though no one had told Henrietta that TeLinde was collecting samples or asked if she wanted to be a donor – Wharton picked up a sharp knife and shaved two dime-sized pieces of tissue from Henrietta's cervix: one from her tumor, and one from the healthy cervical tissue nearby. Then he placed the samples in a glass dish.”

4. Bearing in mind that those two tissue samples removed from Henrietta were *not* removed in an attempt to treat her cancer, but rather purely for purposes of research, was it wrong for the doctor to remove the sample tissue in the first place? Was it wrong for Dr. Gey to collect those samples for the purpose of trying to grow them in controlled conditions? Does the end - i.e., the immeasurable benefit to humankind resulting from those tissue samples - justify the means - i.e., removing tissue from a person without their consent or knowledge?
5. Discuss the process of taking these cancerous cells and growing them in the “auger” or medium that allowed them to continue to multiply. Was it her human cell line?

(Note: As genetic knowledge has increased HeLa is: not really a human cell line at all because it involves a genetic fusion of a papilloma virus and Henrietta's cervical cells. The hybrid has its own genome and attempts have been made to have the cell line recognized as a species in its own right. Of course this cell line also contaminated other cell lines in labs around the world. In a Feb. 2010 paper, HeLa was found as a contaminant of 106 out of 306 cell lines tested.

6. How do you feel about knowing that you still do not have total control over your body once you go to see a doctor? If you discovered that tissue routinely removed from your body at some point in the past went on to significantly benefit science and research, would you feel that you should somehow be compensated? What do you think is more important - a person's personal rights over their own tissue, or contributing to science and research for the benefit of all humankind?
7. When the doctor of the patient, Mr. Moore, lied to him about the financial value of his cells, do you think the doctor behaved unethically, and the court should have ruled against him?
8. Discuss the medical breakthroughs from HeLa cells. Have your attitudes or ideas towards medical research changed in any way due to reading this book?

9. Ownership of genetic material is still a vexed issue. Many human genes have been patented and a battle is currently being fought through the U.S. courts between doctors and a biotech company owning the patents for genes used in breast-cancer research screening. What are your thoughts about research and patents in this now “profit making” industry?

10. Henrietta signed a consent form that said, “I hereby give consent to the staff of The Johns Hopkins Hospital to perform any operative procedures and under any anaesthetic either local or general that they may deem necessary in the proper surgical care and treatment of: _____” (page 31). Based on this statement, do you believe TeLinde and Gey had the right to obtain a sample from her cervix to use in their research? What information would they have had to give her for Henrietta to have given informed consent? Do you think Henrietta would have given explicit consent to have a tissue sample used in medical research if she had been given all the information? Do you always thoroughly read consent forms before signing them?

11. In 1976, when Mike Rogers’s *Rolling Stone* article was printed, many viewed it as a story about race (see page 197 for reference). How do you think public interpretation might have been different if the piece had been published at the time of Henrietta’s death in 1951? How is this different from the way her story is being interpreted today? How do you think Henrietta’s experiences

12. Deborah says, “But I always have thought it was strange, if our mother cells done so much for medicine, how come her family can’t afford to see no doctors? Don’t make no sense” (page 9). Should the family be financially compensated for the HeLa cells? If so, who do you believe that money should come from? Do you feel the Lackses deserve health insurance even though they can’t afford it? How would you respond if you were in their situation?

13. Dr. McKusick directed Susan Hsu to contact Henrietta’s children for blood samples to further HeLa research; neither McKusick nor Hsu tried to get informed consent for this research. Discuss whether or not you feel this request was ethical. Further, think about John Moore and the patent that had been filed without his consent on his cells called “Mo” (page 201). How do you feel about the Supreme Court of California ruling that states when tissues are removed from your body, with or without your consent, any claim you might have had to owning them vanishes?

14. On page 261, Deborah and Zakariyya visit Lengauer’s lab and see the cells for the first time. How is their interaction with Lengauer different from the previous interactions the family had with representatives of Johns Hopkins? Why do you think it is so different? What does the way Deborah and Zakariyya interact with their mother’s cells tell you about their feelings for her?

15. How important is educating American about genes, disease, stem cells or do we leave this knowledge up to the doctors? Explain

16. Pick two or three of the research questions to discuss with your parents. Record their thoughts and bring these to class to enrich our class discussion.