

Who Owns Your Body?

A Look at Property Rights and the Human Body with the Cases of Henrietta Lacks and John Moore

Overview

In 1950, Henrietta Lacks, a young African American woman, entered the colored ward of the Johns Hopkins Hospital to begin treatment for cervical cancer. As she lay on the operating table, a sample of her cancerous cervical tissue was taken without her knowledge or consent and was developed into the ground-breaking HeLa cell line. In 1976, a similar situation occurred when John Moore was treated for cancer at the UCLA Medical Center. His cells were also taken without his knowledge or consent and also used in the creation of a cell line, this one called "Mo." In this lesson, students will examine the details of these two controversial stories through a Power Point presentation, class discussion, reading, and more. Students will grapple with questions such as what level of property rights, if any, a person has to their own body and ultimately, how society should balance interests for the "greater good" with human rights in medical research and experimentation. This lesson will culminate with students participating in a court simulation in which they argue and decide the case of John Moore themselves, finally learning how and discussing how the actual Supreme Court of California actually ruled.

Grades

10 & 11

NC Essential Standards for American History: The Founding Principles, Civics & Economics

- FP.C&G.2.6 - Evaluate the authority federal, state and local governments have over individuals' rights and privileges (e.g., Bill of Rights, Delegated Powers, Reserved Powers, Concurrent Powers, Pardons, Writ of habeas corpus, Judicial Process, states' rights, Patriot Act, etc.)
- FP.C&G.2.7 - Analyze contemporary issues and governmental responses at the local, state, and national levels in terms of how they promote the public interest and/or general welfare (e.g., taxes, immigration, naturalization, civil rights, economic development, annexation, redistricting, zoning, national security, health care, etc.)
- FP.C&G.3.4 - Explain how individual rights are protected by varieties of law (e.g., Bill of Rights, Supreme Court Decisions, constitutional law, criminal law, civil law, Tort, Administrative law, Statutory law and International law, etc.)
- FP.C&G.3.8 - Evaluate the rights of individuals in terms of how well those rights have been upheld by democratic government in the United States.
- FP.C&G.4.4 - Analyze the obligations of citizens by determining when their personal desires, interests and involvement are subordinate to the good of the nation or state (e.g., Patriot Act, Homeland Security, sedition, civil rights, equal rights under the law, jury duty, Selective Services Act, rule of law, eminent domain, etc.)
- FP.C&G.5.2 - Analyze state and federal courts by outlining their jurisdictions and the adversarial nature of the judicial process (e.g., Appellate, Exclusive, Concurrent, Original, types of federal courts, types of state courts, oral argument, courtroom rules, Supreme Court, opinions, Court Docket, Prosecutor/Prosecution, Complaint, Defendant, Plaintiff, hearing, bail, indictment, sentencing Complaint, Defendant, Plaintiff, hearing, bail, indictment, sentencing, appeal, etc.).

NC Essential Standards for American History II

- AH2.H.2.2 - Evaluate key turning points since the end of Reconstruction in terms of their lasting impact (e.g., conflicts, legislation, elections, innovations, leadership, movements, Supreme Court decisions, etc.).

- AH2.H.4.1 - Analyze the political issues and conflicts that impacted the United States since Reconstruction and the compromises that resulted (e.g., Populism, Progressivism, working conditions and labor unrest, New Deal, Wilmington Race Riots, Eugenics, Civil Rights Movement, Anti-War protests, Watergate, etc.).
- AH2.H.8.1 - Analyze the relationship between innovation, economic development, progress and various perceptions of the “American Dream” since Reconstruction (e.g., Gilded Age, assembly line, transcontinental railroad, highway system, credit, etc.).

Essential Questions

- Who was Henrietta Lacks and how were her cells acquired and made into the “HeLa” cell line?
- What is special about the HeLa cell?
- What impact has the HeLa cell had on research, medical advancement, and society as a whole?
- Why did Henrietta and her family know nothing regarding how her cells were being used?
- Who was John Moore and how were his cells acquired and made into the “Mo” cell line?
- What was so special about John Moore’s spleen and cells?
- Why did John Moore sue the UCLA ? What was his argument?
- What decision did the Supreme Court of California make in *Moore vs. the Regents of the University of California*?
- How does the case of John Moore compare to the case of Henrietta Lacks?
- How do research studies and clinical trials contribute to scientific knowledge?
- Describe the level of knowledge, expertise and work on the part of scientists that it takes to develop cell lines such as HeLa and Mo.
- In what ways do current scientific research methods differ from those in the past?
- What level of property rights, if any, does a person have to their own body?
- Ultimately, how should society balance interests for the “greater good” and human dignity in regards to medical research and experimentation?

Materials

- “Who Owns Your Body,” accompanying Power Point; available in the Database of K-12 Resources (in PDF format)
 - To view this PDF as a projectable presentation, save the file, click “View” in the top menu bar of the file, and select “Full Screen Mode”
 - To request an editable PPT version of this presentation, send a request with lesson title to CarolinaK12@unc.edu
- Video of HeLa cells dividing: http://www.youtube.com/watch?v=2mOroGqJ_Uk
 - Teacher note: Many school districts block access to YouTube. Thus, teachers should download the video from a home machine if unable to access the clip at school.
- “Pioneers of Discovery - Henrietta's Dance,” article and questions attached
- Optional: Radio Lab’s “Henrietta’s Tumor,” a 25 minute radiocast available at: <https://www.wnycstudios.org/story/91716-henriettas-tumor>
 - If you are unable to access the link, send an e-mail request for the audio file to CarolinaK12@unc.edu
- “Who Owns John Moore’s Spleen?,” article attached
- Optional: “The Man with the Golden Cells” video, available at: http://www.youtube.com/watch?feature=player_embedded&v=R0o_a4OgOWM.
 - Teachers can play from the beginning, or start the video at 3.23, when the information regarding the John Moore case starts; play till the end. The video then continues at <http://www.youtube.com/watch?v=nV0j36T9wqM&feature=relmfu>. Play from the beginning and stop at 2.18 with “The justice system was about to have its say.” DO NOT play beyond this sentence; students should not hear the actual decision made before they conduct their own court simulation.
- Optional: “Who Told You You Could Sell My Spleen?” from “The Immortal Life of Henrietta Lacks,” by Rebecca Skloot, pages 199-203
- *Moore vs. the Regents of the University of California* Fact Sheet
- Court Simulation Instructions: *Moore vs. The Regents of the University of California*

Duration

2 class periods

Procedure

Day 1

Introduction to the HeLa Cell

1. As a warm-up, tell students to take out a sheet of paper. Play the brief 54 second video at http://www.youtube.com/watch?v=2mOroGqJ_Uk. Without giving students any information regarding the video, instruct them to write down any thoughts regarding what they see and what they think they are viewing. (A few phrases of text will pop up throughout the video that may offer hints to students.) Once the video ends, ask students to share their thoughts. It is likely the word "cell" will be brought up. Discuss:
 - What is a cell?
 - Encourage students to think back to what they have learned in science classes regarding cells. Provide a very basic, brief overview/review, such as:
 - The cell is the basic structural and functional unit of all known living organisms. It is the smallest unit of life that is classified as a living thing, and is often called the building block of life. Organisms can be classified as unicellular (consisting of a single cell; including most bacteria) or multicellular (including plants and animals). Humans contain about 10 trillion cells.
 - What appears to be happening to the cells pictured in the video? Can anyone identify anything special about the cells?
 - Explain to students that the video shows human cells dividing. In particular, the cells were taken from a woman named Henrietta Lacks in 1951. (Project her image on [slide 3](#)). The video shows Henrietta's cells living and dividing outside her body at a rapid pace. The video is actually of a 27 hour segment sped up, during which Henrietta's cells divide, round up, grow hair, and then further divide. Henrietta's cells presented a breakthrough in science and medicine in 1951, because her cells multiplied outside the human body at a rate no one had ever seen before, reproducing an entire generation every 24hours. They were an "immortal cell-line," with the special ability to proliferate continuously, without any mechanisms of prevention.
 - Why do you think finding cells that could be grown and reproduced outside of the human body would be so important to scientific and medical research?
 - Share that during the 1950s, scientist George Gey, head of tissue culture research at Johns Hopkins and his wife Margaret were searching for a tool for the study of cancer: a line of human cells that would live indefinitely outside the body. If they succeeded, they could observe and test human cells in ways they could never do in humans. Eventually, they hoped they could discover the cure for cancer. However, up until 1951, no cells did very well growing outside of the human body. Until Henrietta Lacks's cells came along and changed everything. Henrietta Lacks's cells multiplied like nothing anyone had seen. They latched to the sides of test tubes, consumed the medium around them, and within days, the thin film of cells grew thicker and thicker. On October 4, 1951, George Gey appeared on national television with a vial of Henrietta's cells. He called them HeLa cells, held them up to the camera, and said, "It is possible that, from a fundamental study such as this, we will be able to learn a way by which cancer can be completely wiped out." (Source: <http://www.jhu.edu/jhumag/0400web/01.html>)
 - Do you already know anything about Henrietta Lacks, her cells, and/or the history of how Henrietta's cells were discovered?
 - Tell students that in today's lesson, they are going to be learning more about Henrietta and the HeLa cell. Tell students that while the HeLa cell has been used for much good in the world, the story by which the HeLa cell came about is a complicated and controversial one.
 - Share some introductory information with students, such as:
 - "In 1950, Henrietta Lacks, a young mother of five children, entered the colored ward of the Johns Hopkins Hospital to begin treatment for an extremely aggressive strain of cervical cancer. As she lay on the operating table, a sample of her cancerous cervical tissue was taken

without her knowledge or consent and given to Dr. George Gey, the head of tissue research. [As just discussed,] Gey was conducting experiments in an attempt to create an immortal line of human cells that could be used in medical research. Those cells, he hoped, would allow scientists to unlock the mysteries of cancer, and eventually lead to a cure for the disease. Until this point, all of Gey's attempts to grow a human cell line had ended in failure, but Henrietta's cells were different: they never died. Less than a year after her initial diagnosis, Henrietta succumbed to the ravages of cancer and was buried in an unmarked grave on her family's land. She was just thirty-one years old. Her family had no idea that part of her was still alive, growing vigorously in laboratories—first at Johns Hopkins, and eventually all over the world.” (Source: <http://rebeccaskloot.com/wp-content/uploads/2011/03/RHsklootTeachersGuideLORES.pdf>)

Pioneers of Discovery - Henrietta's Dance

2. Project slide 4 and tell students they are going to begin learning about this controversial piece of history by first reading “Pioneers of Discovery - Henrietta's Dance.” Hand out the article and corresponding questions (attached) and instruct students to carefully read the text, taking notes as they read:
 - Circle any words that are unfamiliar to you.
 - Underline any parts of the article that you think are most important or that stick out to you.
 - If you are confused by any part of the excerpt, write a question mark by that line or section. You can also write out questions on the text.
 - If anything surprises you or evokes a strong emotional response from you, you can write an exclamation mark by the line or section,
 - If a particular thought pops in your head that connects to the reading, write it in the margins.

3. Once students have completed the reading, teachers should either instruct them to answer the corresponding questions individually or in small groups, or teachers can debrief the questions as a whole class. (If students first answer individually or in small groups, teachers should reserve time to address the last five questions in depth as a class.)
 - What was the symptom that caused Henrietta to go to the doctor? When she was examined, what did the doctor's find?
 - What did the doctors use as an attempt to cure Henrietta's disease? How has cancer treatment progressed? What leads to such progressions in medical treatments?
 - Why did George Gey collect human cell samples? What was his goal?
 - What impact did Henrietta's cells have on polio?
 - See #4 below, and slides 6-10 of the accompanying PPT for additional information regarding the impact of HeLa cells on polio.
 - Why did facilities start mass producing Henrietta's cells (named HeLa cells)?
 - As Henrietta's cells were shared with various labs, what other studies were her cells used for?
 - Why did Henrietta's family know nothing regarding how her cells were being used?
 - How did Henrietta's family first learn about how Henrietta's cells were being used (24 years after Henrietta's death)? Why were they so confused by this?
 - What made HeLa cells so special?
 - Why did scientists from Johns Hopkins finally decide to contact the Lacks family?
 - Why did the Lacks family agree to provide the requested blood samples?
 - Even when the Lacks family was finally contacted, why do you think none of the researchers took the time to explain anything to them regarding Henrietta's cells?
 - What are some of the changes in scientific research standards/requirements that have been made, since the doctors took the cells from Henrietta?
 - Why was the Presidential Bioethics Advisory Commission formed?
 - Beyond this article, Rebecca Skloot also wrote a book regarding HeLa cells, called “The Immortal Life of Henrietta Lacks.” Why do you think she feels it is important to bring attention to this story?
 - In your opinion, were Henrietta and her family mistreated by the medical profession? Explain.

- Given that Henrietta Lacks and her family are African American, in what ways might the time period (the 1950s, when segregation was still legal and Jim Crow ingrained in society) have affected this situation? In addition to being African American, do you think the fact that Henrietta and her family was/are poor impacted the way events played out?
 - What positive impact has the medical industry's actions regarding Henrietta's cells had on each of us?
 - Skloot writes, "Since the development of the HeLa cells, there's been an explosion of both scientific and commercial interest in the use of human tissues for research purposes, yet research subjects generally see none of the returns." Should Henrietta's family be compensated in some way for her cells and the impact they have had on research? Why or why not?
 - This quote is located on slide 5 of the accompanying PPT which can be projected during discussion.
4. Discuss with students how it was the HeLa cells' impact on creating a vaccine for polio that first garnered its attention and popularity. Go through the information on slides 6-10 with students to provide a bit more detail regarding polio and the HeLa cells' impact on the disease.
- What are the positive impacts that Henrietta's Lacks's cells have had on society, including on each of us?
 - Describe the level of knowledge, expertise and work on the part of scientists that it took to develop the HeLa cell.
 - Why is this story so complicated? (Discuss with students how it's hard to balance the benefits the creation of the HeLa cell have had on society with the treatment - i.e., lack of informed consent and lack of information shared - of Henrietta and her family. It's not necessarily "cut and dry" on either side.

Optional 25 Minute Activity: Radio Lab's "Henrietta's Tumor"

5. To provide additional details for students, some of which are shared by Rebecca Skloot, author of the *Immortal Life of Henrietta Lacks*, as well as some of the people actually involved in the HeLa story, play Radio Lab's "Henrietta's Tumor" for students, a 25 minute radiocast available at: <http://www.radiolab.org/2010/may/17/henriettas-tumor/>. (Please note that the file is audio only.) Play the file from the beginning, stopping and discussing as directed below:
- *Stop at 7:18 and discuss:*
 - Why did Henrietta Lacks go to Johns Hopkins hospital in 1951?
 - How did George Gey end up with a sample of Henrietta's tumor?
 - What was the main mission of George Gey and other scientists at the time?
 - Why did scientists so badly wanted to be able to successfully grow human cells outside of the human body?
 - Up until Henrietta's cells were introduced, what problem had scientists encountered in trying to grow cells?
 - What happened to Henrietta? What happened to her cells?
 - What turned out to be special about Henrietta's cells?
 - *Continue playing, stopping at 12:27 then discuss:*
 - Why did George Gey send his employee Mary back to the Johns Hopkins morgue?
 - Why couldn't Mary look at Henrietta's body? Why was she so struck by Henrietta's nail polish? Why do you think many people working in fields such as science and medicine try to distance themselves from the human lives connected in various ways to the work they are doing?
 - What did George Gey do with the hundreds of thousands of HeLa cells he produced and why?
 - Why were HeLa cells important to the polio epidemic?
 - What role did the Tuskegee Institute play in using HeLa cells to help create a polio vaccine?
 - In addition to polio, what other diseases were HeLa cells mass produced to study?
 - Why did HeLa cells get sent into space?
 - For an additional reading on the mass production and uses of the HeLa cells, see "The Immortal Life of Henrietta Lacks," Chapter 13: "The HeLa Factory" (p. 93-104).
 - *Continue playing, stopping at 17:10 then discuss:*

- What lead scientists to finally contact the Lacks family 25 years after Henrietta's death?
 - How was Deborah impacted by her mother's death?
 - How do you infer Deborah felt in 1973 when scientists called to request blood samples from the living Lacks family members?
 - Why was she under the misconception that her mother had been cloned?
- *Stop the recording at 25.10 and discuss:*
- What was Henrietta Lacks like (in terms of appearance, personality, etc.)?
 - What was Henrietta's death like?
 - What was Deborah's worry in regards to her mother's cells? Why hadn't anyone explained the science to her?
 - How do you think all the worry and misunderstanding impacted Deborah?
 - What do you imagine it was like for Deborah to see her mother's cells for the first time?

Culminating Discussion & Activity

6. Culminate with a class discussion:

- Bearing in mind that the tissue samples removed from Henrietta were not removed in an attempt to treat her cancer, but rather for purposes of research, do you feel it was unethical for the doctor to remove the sample tissue in the first place? Does the end – i.e., the benefit to society resulting from those tissue samples (i.e. the polio vaccine, etc.) – justify the means – (i.e., removing tissue from a person without their consent or knowledge)?
 - Do you think that Henrietta's race played a part in how the removal of her cells played out? (Meaning, did you get the impression that Henrietta was treated any differently than a well off, white woman would have been treated?)
 - Why has the discovery of the existence of HeLa cells been so difficult for the Lacks family? (Discuss the family's having been kept out of the loop, the vague details that trickled to them second hand, their lack of medical knowledge to understand what they did hear, etc.) Why did it take until 2001, 50 years after Henrietta's death, for a researcher at John Hopkins to show Deborah the cells and explain what they were?
 - Consider Ruth Faden's comment: "There are at least two issues that cases like Mrs. Lacks's raise," says Ruth Faden, executive director of the Johns Hopkins Bioethics Institute and the Philip Franklin Wagley Professor of Biomedical Ethics. "One is the question of consent, and the other is what, if anything, is morally or legally due to a person if something of commercial value is developed from their cells." Do you think the family is owed money for the sale of the HeLa cells? Do you agree with their feeling that they should be compensated?
 - What might be complicated about offering patients money for donations of their cells?
 - Overall, what life lessons can be learned from this account?
- **Optional:** As a culminating assignment, remind students once again that a recent book was written about Henrietta Lacks and the creation of the HeLa cell, called "The Immortal Life of Henrietta Lacks." Tell students to imagine that the author, Rebecca Skloot, has asked them to design the cover for the book. Using their knowledge of the story of Henrietta Lacks and the HeLa cell, while considering all of the layers to the story, students should design a cover for the book on 8 ½ x 11 paper that includes an image and text. The cover should be appropriate to the circumstances of the story and also make readers want to read the book based on its design.

Day 2

7. As a warm-up, have students post their book covers around the class upon entering. Once all covers are hung, instruct students to conduct a five minute gallery walk in which they travel around the room and examine the various book covers. Instruct students to choose one cover (not their own) that they feel does a particularly skilled job at representing the story of Henrietta Lacks. After five minutes, have some volunteers share which cover they felt is most effective and why. Use this as an opportunity to also pose

review questions regarding what students learned the previous day about Henrietta Lacks and the HeLa cell.

The Case of John Moore and the “Mo” Cell Line

8. Next, tell students that they are going to further consider the issues raised in the story of the HeLa cell by considering a similar situation that took place around twenty years later, in 1976, with a man named John Moore. Like Henrietta, John’s cells were taken and used in the creation of a cell line (this one called “Mo”) without his knowledge. However, unlike Henrietta’s situation, John Moore found out and sued the doctor. Explain that they are going to be examining and reenacting the case of John Moore today in class.
9. Begin by providing some background information regarding John Moore’s case by using slides 11-16 of the accompanying PPT. Encourage students to take notes. (The information shared on these slides is also available on the attached “Facts of the Case” handout should teachers want to provide this to students.) After sharing the information, allow students to ask any questions they currently have, but refrain from having a class discussion in which students share their opinions of the circumstances at this point. (There will be time for this after the court simulation.)
10. Next, provide students with the attached article, “Who Owns John Moore’s Spleen?,” which was written in February 1990, right before the California Supreme Court made a decision regarding this case. Instruct students to carefully read the article, reminding them that they will need this information in the upcoming court activity they will be participating in. After students have finished reading, discuss as a class:
 - What was so special about John Moore’s spleen and cells?
 - How might society be negatively impacted if a person with special cells (i.e., cells that could help lead to curing various diseases) is asked to donate those cells but they say no?
 - How much knowledge and work do you imagine it took on Dr. Golde and his team at the University of California to create the “Mo” cell line?
 - In what ways did Dr. Golde profit from the Mo cell line? In what ways did John Moore profit from the Mo cell line? In what ways might society as a whole profit from the Mo cell line?
 - Why did Moore sign the surgical consent form? Why did he initially sign the form provided by Golde’s office regarding giving up his rights to any cell line created? Why did he then change his mind?
 - Why did John Moore sue? What is his argument?
 - What is the legal team for Dr. Golde and the University of California’s argument against John Moore’s case?
 - How might medical research be impacted (positively and/or negatively) if the California Supreme Court makes a decision in favor of John Moore? Likewise, how might individual patients be impacted (positively and/or negatively) if a decision is made in favor of John Moore?
 - What is the National Organ Transplant Act (1984)?
 - What does current law say regarding human property rights in terms of one’s body?
 - Since most research scientists don’t get rich off of cell research, why are they doing this work?
 - Why do many hospitals refuse to incorporate waivers relating to royalty payments into their surgical consent forms?
 - In sum, what are the ultimate questions the California Supreme Court must decide in this case?
 - Make sure students are aware of these three major issues, in addition to any others they may bring up:
 - What level of property rights, if any, does a person have to their own body? (i.e., it’s illegal for someone to remove a healthy organ from me to sell it, but it’s not illegal for medical facilities to use medical waste after my surgery for experimentation)
 - Did John Moore waive all rights to his cells when signing the medical release form for the surgical removal of his spleen?
 - Is John Moore owed compensation based on the commercial development of his cells by Dr. Golde and the University of California?

11. Additional/optional information to share with students:

- “The Man with the Golden Cells”: Additional information regarding the case is available via a brief video, “The Man with the Golden Cells,” available at: http://www.youtube.com/watch?feature=player_embedded&v=R0o_a4OgOWM. Teachers can play from the beginning, or start the video at 3.23, when the information regarding the John Moore case starts; play till the end. The video then continues at <http://www.youtube.com/watch?v=nV0j36T9wqM&feature=relmfu>. Play from the beginning and stop at 2.18 with “The justice system was about to have its say.” DO NOT play beyond this sentence; students should not hear the actual decision made before they conduct their own court simulation.
 - Teacher note: Many school districts block access to YouTube. Thus, if planning to utilize these video clips, teachers may need to download the files from a home computer first.
- “Who Told You You Could Sell My Spleen?”: Another detailed reading is Chapter 25 of Rebecca Skloot’s book, “The Immortal Life of Henrietta Lacks.” Have students read pages 199-203 of the chapter, stopping after 3rd paragraph, ending with “With that, he became the first person to legally stake a claim to his own tissue and sue for profits and damages.” (Make sure students do not read further than this sentence, since the remainder of the chapter discusses the Supreme Court of CA’s decision. Students can finish pages 203-206 of the chapter at the end of the lesson if desired.)

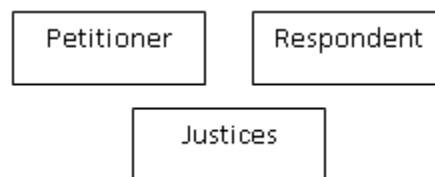
CA Supreme Court Simulation: *Moore v. Regents of the University of California*

12. Remind students that the initial local lawsuit Moore filed never went to trial. Explain that the Los Angeles County Superior Court dismissed it, indicating that because Moore had no property rights to his cells, he had no case. Moore’s attorneys appealed to the California Court of Appeal, which reversed the lower court’s ruling in July 1988. It said Moore did have property rights to his own body. Furthermore, the court said Moore hadn’t waived those rights to his spleen when he signed a form consenting to its surgical removal, and hadn’t agreed to commercial development of his cells by consenting to the surgery or to the medical research that followed. The University of California appealed the ruling to the Supreme Court, in *Moore vs. the Regents of the University of California*.
13. Explain to students that they are going to be determining the outcome of this case themselves. Divide students into groups of 3-5, with an equal number of each type of the following three groups. (Let students know that they may get assigned to a side they don’t necessarily agree with. Explain that they will have a chance to share their own personal opinions at the end of the activity.)
- Legal team for John Moore; these students will argue points such as:
 - the decision of the California Court of Appeal should be upheld,
 - Moore does have property rights to his own body, which were violated by Dr. Golde and his employer, the University of California
 - Moore hadn’t waived his rights to his spleen when he signed a form consenting to its surgical removal, and he never agreed to commercial development of his cells by consenting to the surgery or to the medical research that followed.
 - Moore is owed compensation since Dr. Golde and the University profited from his stolen cells
 - Legal team for Dr. Golde and the University of California medical center; these students will argue points such as:
 - The decision of the California Court of Appeal should be overturned and that the LA Superior Court was correct in their ruling
 - Moore does not have property rights to his own body and Dr. Golde did not violate any law
 - Moore waived his rights to his spleen when it was removed from his body (it was simply medical waste at that point)
 - Moore is not owed compensation; it was Dr. Golde and the University who spent their time and expertise developing Moore’s cell into “Mo.” Moore did nothing to deserve compensation
 - It would be dangerous to medical research to grant patients property rights to their tissues; scientist access to necessary raw materials would become limited and medical advancement as a whole (and society) would thus suffer

- California Supreme Court justices; these students will be responsible for making a decision in the case
- **Teacher note:** If you have a large class, you will likely have 6-9 groups and thus, 2-3 courts will operate around the room at one time. However, if you have a smaller class, you can also choose to make the groups larger (i.e. 5-7 per group) and operate one whole-class court.
14. Provide each team with the attached “Court Simulation Instructions” and go over the court process with students. Tell them that they should refer back to their class notes and discussions, the articles read, or also conduct additional research on the Internet to formulate and back up their assigned side of the argument. Tell students that once they have collected the best reasons supporting their side, they should draft their argument. Though it is brief, encourage students to write their argument in a coherent and eloquent fashion (i.e., begin with an introduction/“hook,” state your arguments and provide supporting evidence with each, and end with a memorable conclusion that the justices will remember.) Finally, remind students of respectful group work expectations and allow them to begin working.
 15. As students work, circulate among each group to ensure they are on track and preparing a coherent argument. Encourage students to think deeply in how to formulate and present their argument. Remind students to consider all of the facts that have been established regarding the case and point out that while teams can make any realistic argument they choose in order to win, they may not argue the accuracy of the facts or falsify any information. Teachers should let students know how much time they have to prepare, using their discretion based on class time available. (Around 15-18 minutes is recommended; give students time updates as they work.)

Conducting the Simulation

16. Once students are ready to conduct the simulation, review class expectations for respectful group work and presentations. If conducting multiple small group courts at once, assign a petitioner group, respondent group, and justice group to various sections of the room and have each court arrange themselves so that the justices are facing the legal teams, who should be separated into two sides facing the justices. (Ensure each court is spread out around the room so as not to interrupt the other courts or overhear other arguments). If conducting one large court, have the justices take seats at the front of the room, with the petitioner and respondent teams facing them on either side of the room.



17. Once all students are in place, teachers should signal the justices to begin proceedings. The chief justice will announce the case to be heard and review the process that will be followed: 5-7 minutes for each side to present their argument, with questions allowed by the justices at any time, followed by 2 minutes for rebuttals and closing statements by each side, and ending with 8-10 minutes of open deliberation and the decision of the justices, during which each side may only listen. After making the expected process clear, the chief justice will call for the petitioner (the legal team for Dr. Golde and the University of CA) to present their argument.
- **Teacher note:** If multiple courts are operating at once, teachers should make sure one of the justices in each group keeps time throughout the proceedings, letting presenters know when they have 2 minutes left and also signaling the teacher when their court session has closed.
18. **Optional:** If groups that finish first need something to do while other groups finish, teachers can instruct students to write a “news blurb” that would be presented on the 5 o’clock news summarizing the proceedings of their court.

19. Once all courts have concluded, bring the students back together for a class discussion of the decision(s) and the proceedings. If multiple courts were enacted, ask the chief justice from each group to summarize the arguments presented, the decision that was made, and the reasoning for the decision. Chart the decisions on the board so students can see the similarities/differences between groups. Discuss as a class:
- Do you think the court made the correct decision in your group? Why or why not?
 - Was anything about this activity difficult? Explain.
 - What makes this case complicated?
 - How do you predict the actual Supreme Court of California ruled?
20. Next, project [slide 17-18](#) and share the Supreme Court of California's actual decision in *Moore vs. the Regents of the University of California* with students. (Teachers can alternatively have students read the end of Chapter 25 of "The Immortal Life of Henrietta Lacks," pages 203-206, which discusses the court's decision.)
- What is your personal opinion of the Supreme Court of California's decision?
 - John Moore said that he felt exploited because his cells were stolen. Why did he feel this way and do you feel that this was a legitimate way for him to feel? Explain.
 - What was the Court most concerned about? In what ways are these valid concerns?
 - How do you feel about knowing that you do not have total control over your body once you go to see a doctor? How might you be negatively impacted by this lack of control? On the other hand, how are you positively impacted?
 - 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?
 - If you discovered that tissue 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? Why or why not?
 - Even though this case was decided in 1990, ownership of genetic material is still a very complicated issue. Many human genes continue to be patented – some lead to great progress in medicine, and with that, they also lead to great wealth for biotech and pharmaceutical companies. What are your thoughts about research and patents when such high levels of profit are made?
21. Finally, ask students to think back to the situation of Henrietta Lacks and discuss:
- How does the case of John Moore compare to the case of Henrietta Lacks? (After students discuss, review the main similarities provided on [slide 19](#).) Does what you've learned regarding John Moore make you think differently about Henrietta Lacks and the HeLa cell in any way? Explain.
 - Think back to Ruth Faden's comment that we discussed regarding Henrietta's Lacks's situation: "There are at least two issues that cases like Mrs. Lacks's raise," says Ruth Faden, executive director of the Johns Hopkins Bioethics Institute and the Philip Franklin Wagley Professor of Biomedical Ethics. "One is the question of consent, and the other is what, if anything, is morally or legally due to a person if something of commercial value is developed from their cells." How does this comment also apply to John Moore's situation?
 - What were some of the differences between Henrietta Lacks's story and that of John Moore?
 - Discuss issues such as the fact that Henrietta died and never knew that the HeLa cell had been created whereas Moore hired a lawyer who discovered the Mo cell line; she nor her family sued whereas John Moore did; she had to be treated in a colored ward of a hospital since she was an African American woman living in the 1950s, whereas John Moore was a white male treated at an integrated hospital of the 1990s, etc.
 - Are there other cases throughout history that you can identify that relate to the issues raised in the stories of Henrietta Lacks and John Moore?
 - The Tuskegee Experiment is an example of people being used as research subjects without their informed knowledge or consent. See the Consortium's "The Tuskegee Syphilis Experiment," available in the Database of K-12 Resources or by sending a request to cnorris@unc.edu.

- How do research studies and clinical trials contribute to scientific knowledge?
- What rules and regulations do researchers follow today when they want to test a new drug or vaccine? Do you think these are effective standards? Why or why not?
 - Optional: Introduce a global component to the discussion of medical studies and trials by asking students whether standards are the same around the world. One perspective on this issue can be read in the *Vanity Fair* article “Deadly Medicine” at <http://www.vanityfair.com/politics/features/2011/01/deadly-medicine-201101>.
- Have your attitudes towards medical research changed in any way due to learning about the HeLa and/or the Mo cell lines and how they came about? Why or why not?
- Ultimately, how do we as a society balance interests for the “greater good” and “human dignity” in regards to medical research and experimentation?

Additional Resources

- Book TV interview with Rebecca Skloot (3/19/2010): <http://www.c-spanvideo.org/program/292685-7>
- *The Immortal Life of Henrietta Lacks*, by Rebecca Skloot
- Website for Rebecca Skloot, which includes links to videos and other resources: <http://rebeccaskloot.com/>.
 - A teacher’s guide, Jeopardy game and more is available on the educators’ page at <http://rebeccaskloot.com/the-immortal-life/teaching/>.
- 'Henrietta Lacks': A Donor's Immortal Legacy: <http://www.npr.org/2010/02/02/123232331/henrietta-lacks-a-donors-immortal-legacy>
- Patent Rights in Biological Material: <http://www.genengnews.com/gen-articles/patent-rights-in-biological-material/1880/>

Pioneers of Discovery - Henrietta's Dance

April, 2000

by Rebecca Skloot

Not long before her death, Henrietta Lacks danced. As the film rolled, her long thin face teased the camera, flashing a seductive grin as she moved, her eyes locked on the lens. She tilted her head back and raised her hands, waving them softly in the air before letting them fall to smooth her curlers. Then the film went blank.

Henrietta danced in Turners Station, a small, segregated Baltimore community where she moved in 1943. She had come by train from a plantation town in Virginia, leaving her kin behind, most still picking tobacco long after freedom from slavery. As she sped toward Baltimore, at the age of 23, her husband, David Lacks, waited in their new brick house with a stove that burned gas instead of wood. Henrietta knew she was heading into a more modern world. What she didn't know was that less than a decade later, after giving birth to her fifth child, her womb would give rise to a new age in medicine.

On February 1, 1951, under the cover of a solitary tree, David Lacks stared through the window of his parked car, watching the rain fall. He and his five children, three still in diapers, sat outside Hopkins Hospital, waiting for Henrietta. A few days earlier, she had found blood spotting her underwear. Now, Howard Jones, a Hopkins physician, found a smooth eggplant-hued tumor glistening under the light on Henrietta's cervix. He touched its surface, shocked by its supple texture, and Henrietta bled. Jones carefully cut a section of her quarter-sized tumor, sent it to the lab for a diagnosis, and sent Henrietta home with her family. Then came the news: the tumor was malignant (cancerous.)

Henrietta returned to Hopkins eight days later. While David and the children waited under the tree, physicians covered her cervix with radium in an attempt to kill the cancer. But before applying the first treatment, a young resident took one more sample. This one went to **George Gey**, head of tissue culture research at Hopkins. He and his wife, Margaret, had been searching for a tool for the study of cancer: a line of human cells that would live indefinitely outside the body. If they succeeded, they could observe and test human cells in ways they could never do in humans. Eventually, they could discover the cure for cancer. They were sure of it. After two decades of failure in their laboratory attempts, the Geys turned their attention to cervical cells, at the request of Richard TeLinde, then Hopkins chairman of Gynecology. TeLinde wanted cervical cells for his own research; the Geys wanted any cancer cells they could get. The day George Gey got his hands on Henrietta Lacks's cells, everything changed. For the Geys, for medicine, and eventually for the Lackses.

Henrietta Lacks's cells multiplied like nothing anyone had seen. They latched to the sides of test tubes, consumed the medium around them, and within days, the thin film of cells grew thicker and thicker. But Henrietta's tumor cells took over her body as quickly as they'd taken over test tubes. Within months, tumors appeared on almost every organ, and Henrietta moaned from her bed for the Lord to help her. The day she died, October 4, 1951, George Gey appeared on national television with a vial of Henrietta's cells. He called them **HeLa cells**, held them up to the camera, and said, "It is possible that, from a fundamental study such as this, we will be able to learn a way by which cancer can be completely wiped out." Gey introduced the nation to his hopes for curing cancer while Henrietta's body lay in the Hopkins morgue, her toenails shining with a fresh coat of red polish. And her family knew nothing of any cells.

As a train carrying Henrietta's casket rolled back toward Virginia, her cells shocked Gey with their strength. The local undertaker met Henrietta's body at the station where, less than a decade earlier, she had boarded her train to Baltimore. He buried her in an unmarked grave across the street from her family's tobacco field, behind the house where her mother was born. But in the Lacks family cemetery, where cattle roam freely when the season's right, folks today don't know much about HeLa. They don't know that soon after Henrietta's death in 1951, Gey and his colleagues used her cells to grow the **polio virus** that was ravaging children throughout the world.

"It was Henrietta Lacks's cells that embraced the polio virus," says Roland Pattillo, a former fellow of Gey's, who is now director of gynecologic oncology at Morehouse School of Medicine. "She made it possible to grow the virus so the **vaccine** could be developed." That was just the beginning. Gey and his colleagues went on to develop a test, using HeLa cells, to distinguish between the many polio strains, some of which had no effect on the human body. Until researchers knew which strain produced polio's crippling effects, they couldn't know what they were fighting. Through Henrietta's cells, they found their culprit. With this information, **Jonas Salk** and his colleague **Albert Sabin** established facilities for the production of polio vaccine before its use in human

Packaged in small glass vials in plastic foam containers, with careful instructions for freezing and handling, shipments of Henrietta's cells went out to Gey's colleagues around the world. . . to Minnesota, New York, Chile, Russia. . .the list goes on. Researchers welcomed the gifts, allowing HeLa to grow. They used the cells to search for a leukemia cure and the cause of cancer, to study viral growth, protein synthesis, genetic control mechanisms, and the unknown effects of drugs and radiation. And though Henrietta never traveled farther than from Virginia to Baltimore, her cells sat in nuclear test sites from America to Japan and multiplied in a space shuttle far above the Earth. Still, David Lacks and his children hadn't a clue.

"The [only thing] I heard about it was, she had that cancer," David Lacks says. "They called me, said come up there because she died. They asked me to let them take samples, and I decided not to let them do it." But the researchers told Lacks they could use his wife's cells to study cancer. Something that might strike his family again someday. Their studies might someday help his children and his grandchildren. Lacks was skeptical. *But, he thought, if they want to see how my wife's cancer might affect our children, and get ready to treat them if they get sick, I guess that might be okay.* "My cousins said it wouldn't hurt, so eventually I let them do it. The [doctors said] it was the fastest growing cancer they'd ever known, and they were supposed to tell me about it, to let me know, but I never did hear."

He didn't hear, that is, until a hazy day in 1975, 24 years after Henrietta's death, when his daughter-in-law went to a friend's house for dinner. In a two-story brown-brick townhouse in Baltimore, five doors down from her home, Barbara Lacks, the wife of Henrietta's eldest son, Lawrence, sat down for dinner at her friend Jasmine's house. The two women had been friends for years, but Barbara had never met Jasmine's sister or brother-in-law, who came all the way from D.C. for dinner. They gathered around the mahogany table, surrounded by plants and soft light, and Jackson, Jasmine's brother-in-law, looked across the table at Barbara.

"You know," he said, "your name sounds so familiar." Jackson was a scientist who spent his days in a Washington laboratory. "I think I know what it is. . .I've been working with some cells in my lab; they're from a woman called Henrietta Lacks. Are you related?"

"That's my mother-in-law," Barbara whispered, shaking her head. "She's been dead almost 25 years, what do you mean you're working with her cells?"

Jackson explained. The cells, he told her, had been alive since Henrietta's death and were all around the world. Actually, by that time, they were standard reference cells--few molecular scientists *hadn't* worked with them. Barbara excused herself, thanking him, promising she would be in touch, and ran home to tell her husband what she'd heard. *Your mother's cells*, she told him, *they're alive.* Lawrence called his father who called his brothers and his sister. They just couldn't understand. "The question I really had," says Barbara, "the question I kept asking Jackson was, I wonder why they never mentioned anything to the family. They knew how to contact us." But, since no one had called in the two decades after Henrietta's death, instead of continuing to wonder, the Lacks family got on the phone and rang Hopkins themselves. And they did it at an opportune time. Henrietta's cells, it turned out, had grown out of control. Some scientists thought her relatives were the only people who could help.

Henrietta's cells were, and still are, some of the strongest cells known to science--they reproduce an entire generation every 24 hours. "If allowed to grow uninhibited," Howard Jones and his Hopkins colleagues said in 1971, "[HeLa cells] would have taken over the world by this time." This strength provided a research workhorse to irradiate, poison, and manipulate without inflicting harm; but it also meant research labs were only big enough for one culture: HeLa.

Though it took three decades for the Geys to succeed with their efforts to create a human cell line, after their success with HeLa, culturing cells became suspiciously easy. Researchers cultivated tissue samples from their own bodies and the bodies of their families and patients. Most grew successfully. Sure, the samples struggled during the first few weeks, or even months, in culture, but then, suddenly, they flourished. Samples blossomed into full-blown healthy cell lines with the strength of, well, the HeLa cell.

In 1974, a researcher at the University of California at San Diego discovered a new type of cancer cell line. For almost three decades, researchers had been using HeLa cells, prostate cells, and other cell lines. To believe this would be to believe that years of work and millions of dollars had, in essence, been wasted.

The truth was, Henrietta's cells had traveled through the air, on hands, or the tips of pipettes, overpowering any cell cultures they encountered. And researchers had no idea. There was no way to know *which* cells were growing in the petri dish. And there was no universally accepted test for a cell culture's identity. To accept or reject the theory that HeLa cells had taken over, researchers wanted more evidence. This required detailed

information about the cells' source. But they knew only the barest facts about Henrietta: She was black, she was a woman, and she was dead.

Though it may have been coincidence, soon after the Lacks children called Hopkins asking about their mother's cells, letters appeared in their mailboxes. Several Hopkins researchers wondered, the letters said, if the Lacks family would be willing to donate some blood and tissue samples. Soon, a nurse circled Barbara Lacks's narrow dining room table with needles, blood tubes, and slides, gathering samples from the Lackses. From these donations, researchers would find precious bits of information about Henrietta--like her blood type--that they could use in their attempts to study her cells.

"[It was] an elegant piece of work," Nelson-Rees told a reporter, "by simple Aristotelian class logic and pure applied genetics, you could speculate, to a remarkable extent, as to what Henrietta Lacks's [genetic makeup] was." And this is exactly what the researchers did. But if you ask the family, you'll get a different story.

"The doctors tested us to see what was in my mother's system, was it hereditary," recalls Henrietta's son Sonny Lacks. "But that's all they said. They never got in contact with us again. We contacted them a couple a times, but they said they'd get back at us, then after a while, we just got tired of calling, so everybody just let it go and went back with their lives." But every now and then, they wonder if they have the gene that killed their mother.

This point of confusion between what the researchers intended to do with the samples and what the participants understood their intentions to be is only one of several elements of the Lackses' story that points to important ethical questions. Some have yet to find answers.

"There are at least two issues that cases like Mrs. Lacks's raise," says Ruth Faden, executive director of the Johns Hopkins Bioethics Institute and the Philip Franklin Wagley Professor of Biomedical Ethics. "One is the question of consent, and the other is what, if anything, is morally or legally due to a person if something of commercial value is developed from their cells."

In terms of **informed consent**, says Faden, "the Lackses' story is a sad commentary on how the biomedical research community thought about research in the 1950s. But it was not at all uncommon for physicians to conduct research on patients without their knowledge or consent. That doesn't make it right. It certainly wasn't right. It was also unfortunately common." Since the era when Henrietta walked through the doors of Hopkins, the field of biomedical ethics was born, and with it came regulations about informed consent. Patients now have something like a legal promise that no physician will take samples without permission. It's the latter issue, the commodification of human body parts, which is still an extremely unsettled area of ethics and law in public policy. And for the Lackses, who don't all have health insurance or the money to afford it, the issue of commercial value in this case is very unsettled. Unsettled, but with little recourse.

Since the development of the HeLa cells, there's been an explosion of both scientific and commercial interest in the use of human tissues for research purposes, yet research subjects generally see none of the returns. "The amazing thing," says Faden, "is that here we are, almost 50 years later, the capacity to develop commercial products from human tissues is dramatically greater now than it was then, and we still haven't figured out how to handle it. . . . In terms of public policy, we're real clear that you can't buy and sell organs, that's illegal. But you can sell blood. You can sell human eggs and sperm. But you can't sell your kidney. And apparently, you can't sell your cells, you give those away. So, nothing is very clear, and there are a lot of deep worries about putting price tags on the human body." This is partially why the United States has recently launched a **Presidential Bioethics Advisory Commission** to address this and related issues.

To this day, members of the Lacks family feel they've been passed over in the story of the HeLa cells. They know their world. They're pretty sure meone wasn't rela ees, a good way to beg rn. This story starts with Henrietta and the origin of the HeLa cells: They were not from Helen Lane or Helen Larson, as many publications have mistakenly reported, they were from Henrietta Lacks, wife of David, mother of five.

Not long before his death, Walter Nelson-Rees, who devoted his career to containing the spread of HeLa cells, sat in a small chair in front of a television camera. He leaned forward, lifted his arms, and said, "HeLa will live forever, perhaps." And then he paused, staring wistfully ahead. "The dance of HeLa continues," he said, "they're all dancing out there somewhere... the stage is very broad and wide, and the curtain has by no means gone down on them. The music plays on." And somewhere, with freshly painted toenails and curlers in her hair, perhaps Henrietta dances with them.

Source: <http://www.jhu.edu/jhumag/0400web/01.html>

- 1) What was the symptom that caused Henrietta to go to the doctor? When she was examined, what did the doctor's find?
- 2) What did the doctors use as an attempt to cure Henrietta's disease? How has cancer treatment progressed? What leads to such progressions in medical treatments?
- 3) Why did George Gey collect human cell samples? What was his goal?
- 4) What impact did Henrietta's cells have on polio?
- 5) Why did facilities start mass producing Henrietta's cells (named HeLa cells?)
- 6) As Henrietta's cells were shared with various labs, what other studies were her cells used for?
- 7) Why did Henrietta's family know nothing regarding how her cells were being used?
- 8) How did Henrietta's family first learn about how Henrietta's cells were being used (24 years after Henrietta's death)? Why were they so confused by this?
- 9) What made HeLa cells so special?
- 10) Why did scientists from Johns Hopkins finally decide to contact the Lacks family?
- 11) Why did the Lacks family agree to provide the requested blood samples?
- 12) Even when the Lacks family was finally contacted, why do you think none of the researchers took the time to explain anything to them regarding Henrietta's cells?
- 13) What are some of the changes in scientific research standards/requirements that have been made, since the doctors took the cells from Henrietta?
- 14) Why was the Presidential Bioethics Advisory Commission formed?
- 15) Beyond this article, Rebecca Skloot also wrote a book regarding HeLa cells, called "The Immortal Life of Henrietta Lacks." Why do you think she feels it is important to bring attention to this story?
- 16) In your opinion, were Henrietta and her family mistreated by the medical profession? Explain.
- 17) Given that Henrietta Lacks and her family are African American, in what ways might the time period (the 1950s, when segregation was still legal and Jim Crow ingrained in society) have affected this situation?
- 18) What positive impact has the medical industry's actions regarding Henrietta's cells had on each of us?
- 19) Skloot writes, "Since the development of the HeLa cells, there's been an explosion of both scientific and commercial interest in the use of human tissues for research purposes, yet research subjects generally see none of the returns." Should Henrietta's family be compensated in some way for her cells and the impact they have had on research? Why or why not?

Notes/Questions:

Who Owns John Moore's Spleen?

February 18, 1990

by J.E. Ferrell

The landmark case-*Moore vs. The Regents of the University of California*-reaches far beyond the primary issue in the case: whether Seattle businessman John Moore has property rights to his spleen.

The case of Moore and his spleen came about because America's founding fathers did not include in the U.S. Constitution any guarantee of people's property rights to their bodies.

Of course, that was 200 years ago, when biotechnology companies didn't exist to develop medical miracles from people's cells. Now they do, and that's how John Moore's spleen has come to be the center of attention.

In 1976, Moore, then 31, suffered from a rare cancer called hairy-cell leukemia. His spleen, which had enlarged to 14 pounds from its normal one pound, was surgically removed at The University of California-Los Angeles Medical Center.

Part of the spleen's job is to destroy worn-out red blood cells. But in hairy-cell leukemia, the organ fills with malignant white blood cells (B lymphocytes) that grow hair-like projections. When the spleen hyperactivates to kill the malignant cells, it kills healthy cells as well. The surgical removal saved Moore's life and put his disease into remission, according to his physician, David W. Golde, a well-known UCLA cancer specialist.

After the surgery, Golde studied a slice of Moore's spleen and found T lymphocyte cells, cells that attack viruses and regulate the immune system. But Moore's T cells were unique. Golde found that they produced a type of blood protein, a lymphokine called GM-CSF that induced the growth of two types of white blood cells that fight bacteria and possibly cancer.

Mo` cells patented

Recognizing the importance of his find, Golde worked for several years to develop a way to reproduce the cells continuously, while Moore, on Golde's request, flew to UCLA several times for removal of more blood, skin, bone marrow and sperm. With an assistant, Shirley G. Quan, Golde applied for a patent on what they called the "Mo" cell line and its products. The patent was awarded to the university in 1984.

Golde contracted with Genetics Institute Inc. of Cambridge, Mass., and Sandoz Pharmaceuticals Corp. of East Hanover, N.J., to develop the Mo cell line into a commercial GM-CSF product. Researchers believe that GM-CSF will have great therapeutic value in building up the blood of cancer patients whose white cells have been destroyed by chemotherapy. It may even have application in fighting certain cancers, and may help AIDS patients ward off infection.

As part of the agreement, Golde paid a nominal sum for 75,000 shares of Genetics Institute stock worth more than \$2 million today. Genetics Institute also paid Golde and the university \$330,000 over three years to fund his laboratory. Sandoz Pharmaceuticals provided \$110,000.

Moore was never told that his cells had commercial value. Although that value has been estimated at \$3 billion, competing companies are developing similar products that may reduce that amount. Clinical trials of GM-CSF are continuing, and Sandoz Pharmaceuticals, the company to whom Genetics Institute licensed GM-CSF, is expected to apply for U.S. Food and Drug Administration approval this year to market the product, according to a Genetics Institute spokesperson.

In 1983, Moore was asked to sign a form granting to the university any rights he might have to the cell line developed from his blood. He did not waive his rights. Later, when Golde asked him to correct his "mistake,"

Moore became cases.

1 medical

When Moore found out what Golde had been doing, he sued Golde and the University of California for lack of informed consent, fraud and deceit, as well as what, in legal terms, is called "conversion." In other words, Moore says that Golde stole his property - his spleen cells.

`No rights, no case`

The lawsuit never went to trial. The Los Angeles County Superior Court dismissed it, indicating that because Moore had no property rights to his cells, he had no case.

Moore's attorneys appealed to the California Court of Appeal, which reversed the lower court's ruling in July 1988. It said Moore did have property rights to his own body. Furthermore, the court said Moore hadn't waived those rights to his spleen when he signed a form consenting to its surgical removal, and hadn't agreed to commercial development of his cells by consenting to the surgery or to the medical research that followed. The University of California appealed the ruling to the Supreme Court, which is to hand down its decision this summer.

"Obviously, we agree with the court of appeal," says California Jonathan Zackey, an attorney who, with Gage, will argue the case before the California Supreme Court. "Who should have more property rights (to the spleen cells) than the source? They (Golde and Quan) didn't invent his (Moore's) cells. They found his cells, grew and observed his cells."

Nonsense, say attorneys for Golde and the university. Moore made no contribution to society, argues the university's attorney, Allen B. Wagner. Golde and Quan did all the work. Moore relinquished rights to his diseased spleen once it left his body.

Bsides, the attorneys argue, the Mo cell line no longer contains any of Moore's cells; the researchers are just using the genetic information from those cells to continue the cell line by cloning. The view of the Industrial Biotechnology Association is that if every scientist must negotiate property rights to every individual's tissue, medical research will be impeded.

Laws regarding the use of human tissues have evolved with medical science. Out of the need for tissue for research and transplantation emerged the Uniform Anatomical Gift Act- adopted by all 50 states by the end of the 1960s-which permits competent adults to donate, upon death, all or any part of their bodies to medicine.

Precedents unclear

With transplants becoming so common, the unpleasant specter of a market in body parts prompted Congress to pass the National Organ Transplant Act in 1984 to prohibit the sale of a human kidney, liver, heart, lung, pancreas, bone marrow, cornea, eye, bone or skin for transplant. However, the law does not apply to sales of human tissues and cells for research or commercial purposes that do not involve transplants.

Although no laws directly address humans' property rights to their own bodies, they require that people give their informed consent before any tissues are removed, and that relatives of the dead be consulted to determine disposal of a cadaver, to which they have "limited" property rights.

It is the advent of new technologies that is pushing the legal envelope once again. Scientists can now isolate infinitesimally small amounts of human biological substances, develop human cell lines, isolate genes and generate large amounts of the substances they produce through genetic engineering. A 1986 Congressional survey found that, of 81 medical institutions queried, about half use human tissues in research; of 939 patents applied for by those institutions between 1980 and 1985, 211 included human tissues.

So far, the legal conflicts have been few. According to Robyn Nishimi, a project director at the U.S. Office of Technology Assessment, in only three cases before Moore was ownership of human tissues contested. All three were settled out of court and involved disputes between research scientists or their organizations. Except for one case in which the researcher's mother provided the cells, neither the people from whom the cells were taken nor their families were involved.

Greedy opportunists?

Now that *Moore vs. The Regents of the University of California* is bringing the issue of people's property rights to their own bodies into the open, does the dispute suggest that all research physicians are greedy opportunists who view patients in terms of the number of Mercedeses their cells can provide?

Not at all, says Brent Kopp, director of management systems in the University of Maryland pathology department, which he describes as the gateway through which that school's medical researchers obtain human tissue for research. "I see few wildly successful scientists. Maybe 20 people out of 50,000. The rest build medical knowledge slowly, piece by piece."

Most research physicians use anonymous human tissues obtained from hospitals for basic research. Several non-profit organizations have emerged to grow and provide cell cultures, tissue and cloned genes for researchers.

For example, some research physicians want any lung tissue that's been diseased by asbestiosis. Others request any cancerous colon tissue. Some of the research involves testing of diagnostic or therapeutic agents that must be shown to work in almost any person who has the same disease.

Some companies want tissue to test research instruments. They need masses of unidentified blood to develop a machine that analyzes blood, for example. Suppliers include blood banks with unusable old blood and hospitals that would otherwise discard blood leftover from clinical laboratory tests.

Still, John Moore's lawsuit has prompted the some of the few biotechnology companies that deal in unique cell lines to protect themselves from similar lawsuits. "I know of two biotechnology companies that have royalty agreements with people," says Marvin Guthrie, director of the Office of Technology Affairs at the Massachusetts General Hospital in Boston. He refused to identify them.

People as products

Some hospitals have been approached by companies looking for individually identified tissues and asking for guarantees that the tissues are free of legal entanglements. The hospitals have refused to provide tissue to the companies because they don't believe that a hospital can waive any legal rights of a patient.

In addition, those hospitals refuse to incorporate waivers relating to royalty payments in their surgical consent forms. They say it interferes with the patient-doctor relationship, especially if the patient wonders if, by refusing to waive rights to tissue, he risks that his physician won't perform medical procedures properly.

Nevertheless, the tendency of the medical profession to regard people as products is growing, especially once that tissue leaves a person's body.

A recent case in Norfolk, Va., pitted a fertility clinic against a couple who had frozen embryos stored at the facility. The couple moved to California, and wanted a clinic near their home to complete the implantation of the embryos. The Virginia clinic refused to release the embryos to the couple. A judge determined the embryos were the property of the couple.

“The judge used the California Court of Appeal ruling in the Moore case in his decision,” says attorney Lori Andrews, a research fellow at the American Bar Foundation in Chicago. Andrews has filed a brief in support of John Moore on behalf of the 85,000-member People’s Medical Society in Allentown, Pa., the nation’s largest consumer health care organization. “We’re not asking for a return to the status quo,” she says.

Andrews points out that the ruling will affect abortion, fetal tissue, frozen embryos, eggs and sperm “in the sense of recognizing that patients control what is done to their bodies.”

But, she notes, dangers exist in regarding human tissues the same way we regard television sets and automobiles. “Perhaps it should be a limited form of property,” Andrews says, arguing that the only person allowed to make a decision about his or her body tissues would be that individual. “We don’t want hospitals holding people hostage for their valuable organs if they didn’t pay their bills.”

Source: http://articles.chicagotribune.com/1990-02-18/features/9001140537_1_mo-cell-line-blood-cells-spleen

Notes/Questions:

- In 1976, thirty-one year old **John Moore** visited his doctor due to disturbing symptoms he had developed. His gums were bleeding, his belly was swelled, and he had bruises covering his body.
- Moore was diagnosed with **hairy-cell leukemia**, a rare and deadly cancer that caused his spleen to fill with cancerous cells until it bulged like a blown-up balloon
- Moore's local doctor referred him to **Dr. David Golde**, a prominent cancer researcher at the UCLA Medical.
- Moore made an appointment and first saw Dr. Golde on October 5, 1976. After hospitalizing Moore and taking blood, bone marrow, and other fluid samples, Dr. Golde confirmed the diagnosis and told Moore his life was in danger based on his condition.
- On October 8, 1976, Dr. Golde recommended that the best course of treatment was to remove Moore's spleen, which would slow down the progression of the leukemia. (Whereas a normal spleen weighed less than a pound, Moore's weighed 22 lbs.)
- Moore signed a written consent form authorizing the splenectomy, which also said the hospital could "dispose of any severed tissue or member by cremation".
- Surgeons at UCLA Medical Center removed Moore's spleen on October 20, 1976.
- After the surgery, Moore moved to Seattle. However, Dr. Golde instructed Moore to return to UCLA several times between November 1976 and September 1983. Dr. Golde explained that such visits were necessary and required for Moore's health and well-being, and that they should only be performed at UCLA by Dr. Golde. Thus, Moore would fly from Seattle back to Los Angeles, where Dr. Golde withdrew additional samples of blood, blood serum, skin, bone marrow, and other fluids during each visit.
- When Moore told Dr. Golde he wanted to continue his follow-up appointments at home, Dr. Golde offered to pay for the plane tickets and put him up at the prestigious Beverly Wilshire hotel.
- In 1983, Moore was given a consent form that said:
 "I (do, do not) voluntarily grant to the University of California all rights I, or my heirs, may have in any cell line or any other potential product which might be developed from the blood and/or bone marrow obtained from me."
- The first time Moore was presented with the form, he circled "do," later explaining why by saying, "You don't want to rock the boat. You think maybe this guy will cut you off, and you're going to die or something." However, Moore was feeling that something wasn't right, and so at his next appointment when he was given the same form, he marked "do not."
- After his appointment, Moore returned to his parents' home nearby, where Dr. Golde's office had already left several messages for him. Dr. Golde explained that Moore had made a mistake by choosing "do not" and asked Moore to return to the office to redo the form.

- When Moore said he didn't have time to return, Dr. Golde mailed him the form with instructions that said, "Circle 'I do.'" Now very suspicious, Moore turned the form over to an attorney, who discovered that Dr. Golde had devoted much of the seven years since Moore's surgery to developing and marketing a cell line called "Mo" from the bodily samples he had been collecting from Moore.
- Dr. Golde and his associate, Shirley Quan, had applied for a patent on the cell line on January 6, 1983. The patent for "Mo" was issued on March 20, 1984.
- With the Regents' assistance, Golde negotiated agreements for commercial development of the cell line and products to be derived from it. Under an agreement with Genetics Institute, Golde became a paid consultant and acquired the rights to 75,000 shares of common stock (worth 2 million \$ today). Genetics Institute also agreed to pay Golde and the Regents at least \$330,000 over three years, including a pro-rata share of Golde's salary and fringe benefits, in exchange for exclusive access to the materials and research performed on the cell line and products derived from it.
- When Moore found out what Golde had been doing, he sued Golde and the University of California for lack of informed consent, fraud and deceit, and "conversion." (In other words, Moore says that Golde stole his property - his spleen cells.)
- The lawsuit never went to trial locally. The **Los Angeles County Superior Court** dismissed it, indicating that because Moore had no property rights to his cells, he had no case.
- Moore's attorneys appealed to the **California Court of Appeal**, which reversed the lower court's ruling in July 1988. It said Moore did have property rights to his own body. Furthermore, the court said Moore hadn't waived those rights to his spleen when he signed a form consenting to its surgical removal, and hadn't agreed to commercial development of his cells by consenting to the surgery or to the medical research that followed.
- The University of California appealed the ruling to the Supreme Court, which handed down its decision in the summer of 1990.

Notes:

Court Simulation Instructions: ***Moore vs. the Regents of the University of California***

You will be participating in the California Supreme Court case of *Moore vs. the Regents of the University of California*. Your group will be assuming the role of one of the following:

- Legal team for John Moore (respondent/appellee)
- Legal team for Dr. Golde and the University of California medical center (petitioner/appellant)
- California Supreme Court justices

Take the following steps to prepare:

1. Review and clarify the facts of the case by discussing with your team:

- What happened in this case? Who are the people and organizations involved?
- How did the California Court of Appeals rule in this case?
- What does each team want as an outcome in *Moore vs. The Regents of the University of California*

2. Review the issue(s) to be decided in the case:

- What level of property rights, if any does a person have to their own body?
- Did John Moore waive all rights to his cells when signing the medical release form for the surgical removal of his spleen?
- Is John Moore owed compensation based on the commercial development of his cells by Dr. Golde and the University of California?

3. Prepare for the court simulation:

- **Legal Teams:** Prepare arguments for your side of the case. Select one or two students to present the arguments to the court. When discussing the arguments, consider:
 - What does your team want? (How do you want the justices to rule?)
 - What are all of the possible arguments that you can make to help prove your side of the case?
 - Are there current laws or other cases that are relevant to this case? If so, how can you use this as evidence to win?
 - Which of your arguments are the most persuasive? Why? (When preparing your presentation, you'll want to start with/focus on these.)
 - What does the other side want? What arguments might they use to try to convince the justices to rule in their favor? (You'll want to spend some time trying to contradict these in your own arguments and/or rebuttal.)
 - What are the possible negative consequences if the justices rule in favor of the other side? (Consider the consequences not just to your client, but also to society in general.)

Once your team has collected your best reasons for why the court should decide in your favor, draft your argument. You will have 5-7 minutes to present your argument and convince the justices. Your argument should be written and delivered in a coherent and eloquent fashion. It is recommended that you begin with an introduction/hook, state your arguments and provide supporting evidence with each, and end with a memorable conclusion.

** Make sure your team considers all of the facts that have been established regarding the case. While teams can make any realistic argument they choose in order to win, you may not argue the accuracy of the facts or make up information.

- **Supreme Court Justices:** Discuss what you think both sides of the argument are that will be presented to you today, as well as the issues involved. Further, predict what you think each side will be seeking and discuss whether there are any alternatives. Prepare at least 5 questions for each side that you will need answered in order to reach a decision.

Select one student in your group to serve as chief justice. The chief justice will preside over the hearing. He or she will open the proceedings when it is time to begin, call for each side to present its case, as well as ask questions and recognize other justices to ask questions.

Select a second person to serve as a time keeper. This person will be responsible for monitoring the presentation time of each legal team. (5-7 minutes for each opening argument; 2 minutes for rebuttals and closing; 8-10 minutes for deliberation of the justices).

4. Court simulation procedure:

When it is time to begin the court proceedings, the chief justice will ask each side to present its arguments, starting with the petitioner (Dr. Golde's team) and then followed by the respondent (John Moore's team.) The justices may ask questions at any time.

- Each side will have five to seven minutes for its initial argument. During and/or after each presentation, the justices can and should question the attorney in an effort to clarify the arguments. (Attorneys may ask for time to consult with other members of their team before answering questions.)
- After each argument has been presented, each side can then have up to two minutes for a rebuttal and closing statement.
- After the rebuttals, the justices will have 8-10 minutes to openly deliberate their decision. The legal teams should listen at this point, without talking or interrupting the deliberations of the court. The justices should discuss all of the arguments and close with a vote on a decision. Each justice should give reasons for his or her decision when expressing his/her final vote.
- The chief justice should then tally the votes and announce the decision of the court and the most compelling arguments for that decision. (A decision is reached by a majority of votes.)
- The chief justice should then formally summarize/announce the decision to the legal teams. A dissenting opinion may be given. (Meaning, if the justice(s) in the minority strongly disagree with the decision the majority made, he/she can say so and explain why.)

What questions do you have about this activity?