

#### PPT ACCOMPANIMENT FOR CAROLINA K-12'S LESSON

#### WHO OWNS YOUR BODY?

A LOOK AT PROPERTY RIGHTS & THE HUMAN BODY WITH THE CASES OF HENRIETTA LACKS & JOHN MOORE

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#### WARM UP



• <u>http://www.youtube.com/watch?v=2mOroGqJ\_Uk</u>



### "PIONEERS OF DISCOVERY -HENRIETTA'S DANCE"

- Carefully read the article, taking notes on the text:
  - 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.



"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."

~Rebecca Skloot



# POLIO

- Polio is a viral infection of the central nervous system. While polio was a worldwide epidemic between 1840-1950, and no cure exists, it has largely been eradicated by vaccination in modern times.
- The virus spreads by direct person-to-person contact, by contact with infected mucus or phlegm from the nose or mouth, or by contact with infected feces. The virus has many strains, some of which have no symptoms, whereas other strains can cause paralysis or even death.
- Those most likely to get the disease were/are children, pregnant women, and the elderly.
- By the end of 1951, the world was in the midst of the biggest polio epidemic in history. Schools closed, parents, panicked, and the public grew desperate for a vaccine.
- In February 1952, Jonas Saulk announced that he'd developed the world's first polio vaccine, but he couldn't begin offering it to children until he'd tested it on a large scale to prove it was safe and effective. And doing that would require <u>culturing cells on an enormous, industrial</u> scale, which no one had done before.



Iron lungs were used to treat respiratory failure associated with polio

### HENRIETTA'S CELLS & POLIO

Not long after Henrietta's death, planning began for a HeLa factory—a massive operation that would grow to produce trillions of HeLa cells each week. It was built for one reason: to stop polio. —The Immortal Life of Henrietta Lacks, pg. 93

- 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."
- 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.
- With this information, **Jonas Salk** and his colleagues in Pittsburgh created a vaccine, and the National Foundation for Infantile Paralysis established facilities for <u>mass-producing the HeLa cells</u>. They would use them to test the polio vaccine before its use in humans.

# THE TUSKEGEE INSTITUTE & HENRIETTA'S CELLS

- Prior to becoming President, Franklin Roosevelt had established the Georgia Warm Springs polio rehabilitation center which maintained a White's only policy of admission. There was an assumption that Polio was only a White disease.
- In 1941, the Tuskegee Infantile Paralysis Center opened to train Black doctors and physical therapists.
- In 1953, the Tuskegee Institute established facilities for mass production and distribution of HeLa cells, which they shipped (to the tune of 600,000 cultures) around the country.

"Black scientists and technicians many of them women, used cells from a black woman to help save the lives of millions of Americans, most of them white. And they did so on the same campus – and at the same time – that state officials were conducting the infamous Tuskegee syphilis studies."

-The Immortal Life of Henrietta Lacks, pg. 97

#### HENRIETTA'S CELLS HELP DIMINISH POLIO CASES

- Since the development of polio vaccines, the incidence of the disease has been greatly reduced. Polio has been wiped out in a number of countries. There have been very few cases of polio in the Western hemisphere since the late 1970s.
- Children in the United States are now routinely vaccinated against the disease. Outbreaks still occur in the developed world, usually in groups of people who have not been vaccinated.
- Thanks to a massive, global, vaccination campaign over the past 20 years, polio exists only in a few countries in Africa and Asia.



# BEYOND POLIO...

- Packaged in small tubes tucked in plastic foam containers, with careful instructions for feeding and handling, shipments of Henrietta's cells went out to Gey's colleagues around the world.
- 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.
- Though Henrietta herself 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.
- Yet all the while, David Lacks and his children hadn't a clue that their mother's cells were being used in this way.



- 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 pds.!)
- 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 plan 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 collected 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).

#### UNITED STATES PATENT AND TRADEMARK OFFICE CERTIFICATE OF CORRECTION

PATENT NO. : 4,438,032 DATED : March 20, 1984 INVENTOR(S) : David W. Golde et al.

It is certified that error appears in the above-identified patent and that said Letters Patent is hereby corrected as shown below:

On the title page of the patent add as a second paragraph to the ABSTRACT:

--The Mo line has been deposited at the A.T.C.C. on June 3, 1981, with the Accession No. CRL 8066.--

> Signed and Sealed this Nineteenth Day of March 1985 Attest: DONALD J. QUIGG Attesting Officer Acting Commissioner of Patents and Trademarks

 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.

[SEAL]

- 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 *Moore vs. The Regents of the University of California* the summer of 1990.

# MOORE VS. THE REGENTS OF THE UNIVERSITY OF CALIFORNIA

- Nearly seven years after Moore originally filed suit, the Supreme Court of California ruled <u>against him</u>, overturning the ruling by the lower California Court of Appeal.
- The Court decided that when tissues are removed from your body, with or without your consent, any claim you might have had to owning them vanishes.
  - When you leave tissue in a doctor's office or lab, you abandon them as waste, and anyone can take your garbage and sell it. Since Moore had abandoned his cells, they were no longer a product of his body, the ruling said.
  - They had been "transformed: into an invention and were now the product of Golde's "human ingenuity" and "inventive effort.""
- Moore wasn't awarded any of the profits.

### MOORE VS. THE REGENTS OF THE UNIVERSITY OF CALIFORNIA

- The Court did however agree with Moore on two counts:
  - Lack of informed consent, because Golde hadn't disclosed his financial interests
  - Breach of fiduciary duty, meaning Golde had taken advantage of his position as doctor and violated patient trust
- The Court said that researchers should disclose financial interests in patient tissues, though no law requires it. It also pointed out the lack of regulation and patient protections in tissue research, and called on legislators to remedy the situation.
- However, the Court argued that ruling in Moore's favor might "destroy the economic incentive to conduct important medical research," and that giving patients property rights to their tissues might "hinder research by restricting access to the necessary raw materials," creating a field where "with every cell sample a researcher purchases a ticket in a litigation lottery."
- "Scientists were triumphant, even smug. The dean of the Stanford University School of Medicine told a reporter that as long as researchers disclosed their financial interests, patients shouldn't object to the use of their tissues. "If you did," he said, "I guess you could sit there with your ruptured appendix and negotiate."
- Moore tried to repeal his case to the US Supreme Court, who refused to hear the case.

# SIMILARITIES BETWEEN HENRIETTA LACKS'S & JOHN MOORE'S SITUATIONS

# **<u>Similarities</u>** between Henrietta Lacks's and John Moore's stories:

- Lack of informed consent in both cases in both cases, the physician who created the cell line from tissue taken from his failed to ask permission
- In both cases, patients (or family) were given no information about the use of the cells in research.
- In both cases, some groups made a lot of money from the cell lines- In Henrietta Lack's case, it wasn't actually the doctor who made the cell line, but rather the supply companies that provided researchers with the cell line that profited most. In John Moore's case, it was his physician—as well as his physician's employer, the University of California, as well as a private company, that made a lot of money.

#### RESOURCES

- "The Immortal Life of Henrietta Lacks," by Rebecca Skloot
- http://fyb.umd.edu/HeLa/polio.html
- http://www.radiolab.org/2010/may/17/henriettas-tumor/
- http://rebeccaskloot.com/
- http://www.npr.org/2010/02/02/123232331/henrietta-lacksa-donors-immortal-legacy
- http://www.genengnews.com/gen-articles/patent-rights-inbiological-material/1880/