

Henrietta Lacks Lesson

Volume 3



Cervical Cancer and the HPV Perspective



National Human Genome
Research Institute

The **Forefront**
of **Genomics**

Cover

Portrait of Henrietta Lacks by Kadir Nelson/Smithsonian

Foreword

What we say is that she was good during her living days and she's still good in her dying days. My grandmother may have passed, but she's still helping people. That's the kind of person that she was. But, for many years, we knew very little about her. We had a picture of a good looking young woman, well dressed and beaming, but we were missing the stories to make her real. It was only with the publication of *The Immortal Life of Henrietta Lacks* that I really met my grandmother. I learned about my grandmother at the same time that I learned about the HeLa cells and the controversy that surrounded them. With all the questions that the HeLa cells created, and the confusing and painful relationship that the family had with researchers who would come to take samples and leave empty promises to bring back answers, in a way, without them, I would still not know my grandmother.

Henrietta always made sure that everybody was taken care of and her story hasn't ended. She continues to contribute to the world through her cells and we, her kids and grandkids, are doing what we can to walk beside her. We keep her story alive, so others can remember and learn from it, and we use this story as a platform to advocate for a diverse collection of other important issues, such as patient rights, consent, disease prevention, and health disparities. My brother goes around talking about the importance of participating in clinical trials. There remains so much distrust in the African American community toward the medical establishment, but being represented in these studies is an important step in making sure that medical breakthroughs also work for us. My cousin has the Henrietta Lacks House of Healing, a place to help previously incarcerated men and women successfully transition back into the community. It's important to us to bring awareness and to make sure that everyone is given the opportunity to take care of their health.

At the root of it, this is an issue of ownership and control over your own information. My brother is involved with the HeLa Genome Data Access Working Group, which reviews requests by research groups seeking access to the HeLa genome. It is important to him that the family have a say in how this resource, our grandmother, is used by others (universities, government laboratories, companies, etc.). For me, it's more about the personal side. I tell my grandmother's story and try to help where I can, where it comes to educating the public about health disparities and disease prevention. Our experience has made me more vigilant: when I go to the doctor, or when I take my mother to the doctor, I'm much more proactive about asking questions, looking up information about the treatment they recommend, making sure that things are not overlooked. These practices are steps that we can all take to protect our bodies and our health.

When I think about Henrietta's story and legacy, two words come to mind: "hope" and "everlasting". When I see all the ways that the HeLa cells have helped people, through discoveries that have made in vitro fertilization possible, or vaccines, or cancer treatments, I see hope. Hope for people and hope for the future. An important part of this story is compassion. When I tell Henrietta's story, I want people to remember that this was an African American woman with limited education and limited income. The difference she has made is tremendous, but the way she and her family were treated was regrettable. I hope students realize that this could have happened to anyone – their parent, their grandparent, themselves. We should show compassion to the people we meet and the people around us. Henrietta didn't choose this, but this is all part of her story now. I hope she never stops doing good and helping people. That is who she is. This is my grandmother.

by Jeri Lacks-Whye

Curriculum Introduction

In 1951, a young woman sparked a scientific revolution. Unfortunately, she would neither know about it nor benefit from it. For many decades, we would not even know her name. The life of this young woman, Henrietta Lacks, was cut short by the ravages of a rapidly advancing cancer colonizing her body. As the cancer was quickly killing Henrietta, a piece of her tumor was isolated and grown in a test tube. As it happened, the traits that made her cancer cells grow so rapidly also granted them the unusual ability to grow rapidly under artificial laboratory conditions outside of her body and without dying; a scientific phenomenon at the time. A new world of scientific tools was suddenly available to researchers. However, the life of Henrietta Lacks is part of a larger and more complex story. Despite the fact that her disease was of great scientific benefit, her story is not confined to this terrible and terminal experience.

In many ways, Henrietta Lacks' story is the story of early 20th century America for African Americans; a story of struggle, inequality, segregation, and racism in our history. Henrietta Lacks was a young African American woman who grew up in Virginia during the Jim Crow era. Having hoped to emerge from slavery into some semblance of freedom, many African Americans in the South at the end of the 19th century found themselves thrust into a new form of bondage as sharecroppers and in perennial debt to white landowners. In order to improve her family's prospects, she moved with her husband and two young children to Baltimore to begin a new, and hopefully, better life. While the move did not take her out of the South, it did transport her from life on a tobacco farm in rural Virginia to a booming industrial port city. In these details, Henrietta's life was reminiscent of the struggles and displacement of countless other African Americans in the United States at that time. Many African Americans during this time period began leaving the rural South in favor of Northern urban centers, dramatically changing the social landscape of the United States.

Even at the end of her life, Henrietta's experiences illuminate the details of life as an African American and as an African American woman, as well as the realities of science and medicine in Baltimore for people of color at that time. Henrietta Lacks was diagnosed with an aggressive cervical cancer, for which the accepted treatment at the time was the implantation of vials of radioactive material within the cervix. While this treatment was the current medical standard of care, the fact that Henrietta had to receive this treatment in a segregated ward at Johns Hopkins University Hospital was not out of medical necessity. These trappings of segregation were the outward expressions of a mindset that has been a part of the American experience since its inception; and, indeed, the United States is not the only place in which these prejudices have made a home. However, the intersection of racism with science and medicine is particularly insidious. This intersection gave implicit license to doctors conducting unethical studies on unsuspecting African American patients in Alabama, in what would be called the Tuskegee Syphilis Experiment, as well as a litany of other inexcusable incidents that have tarnished the image of the scientific and medical establishments over the decades. Several years before Henrietta's death, in response to the horrific exploits of Nazi doctors during the Second World War, the Nuremberg Laws codified a handful of basic tenets of medical ethics. The first of these tenets requires patient consent before an experiment or procedure is carried out. Less than ten years after these laws were in place, Henrietta's cells were isolated, grown, and disseminated around the world without her consent or knowledge.

Despite the manner in which Henrietta's cells were obtained and propagated, the scientific advances attributed to her cells cannot be understated and also comprise part of the lasting legacy she leaves behind. The cancer cells that tormented Henrietta in life and were fashioned into tools of biomedical science after her death have allowed us to better understand cancer, discover and produce vaccines, and understand basic details of the inner workings of the cell. Furthermore, they have allowed the establishment of countless other cell lines, which are indispensable in the modern study of human health and disease.

This curriculum will explore a variety of topics that interconnect through Henrietta's life and experiences and will highlight the importance of these topics to our current understanding of science and society. Students and teachers will explore how prejudices impact individuals and societies, directly and indirectly, as well as attempt to understand Henrietta's personal experiences as she moved away from Virginia. Henrietta died of an aggressive form of cervical cancer and students will be guided through an exploration of our current understanding of how cancer comes about and may be treated. Years after the original diagnosis, scientists identified human papillomavirus (HPV) living within Henrietta's cells and this virus may have been responsible for making her disease more aggressive. Students will explore our current understanding of the link between HPV and cancer.

HeLa cells, as Henrietta's cells have been dubbed, are sometimes referred to as her immortal life; the physical part of her that will continue to live forever. However, Henrietta's true immortality is achieved through memory. She is immortal in that her name is on the lips of every student in a biology class, every scientist and doctor who wishes to save or improve a life, every social scientist who aims to learn from our past to fashion a better future. It is said that he who saves one life, it is as if he had saved the entire world. Henrietta has saved countless lives, and she is not done quite yet.

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Introduction

The cancer that took the life of Henrietta Lacks was very aggressive; first, as it tormented Henrietta, but also as it grew in the laboratory. Within a short time of the distribution of these cells worldwide, reports began showing that HeLa cells have “invaded” other cultured cell lines. Specifically, it is believed that over half of all cell lines in some laboratories and repositories are, in fact, HeLa cells (regardless of what the label on the bottle may state). Years after the original inspection of Henrietta Lacks’ cancer, researchers were able to detect Human Papillomavirus (HPV) within the tumor. It is not known if HPV is related to the hardiness of HeLa cells, but the link between HPV infection and the development of certain cancers has been the focus of intense study in recent years. Viruses hijack the machinery of the cell for their own benefit. Some viruses stay in their host cells only briefly, subverting the cells until the cells can no longer keep up; they then escape the dying remains of the cells to seek new cells to infect. Other viruses stay in their hosts for extended periods of time, either remaining dormant until awakened again or slowly building up their strength while avoiding detection. One strategy to propagate while remaining inconspicuous may be to take advantage of cells that do exactly that - replicate uncontrollably while evading the body’s defenses: cancer cells.

This unit will explore the links between HPV and cervical cancer. While there is a vaccine available for HPV, this unit will also explore reasons why HPV and the HPV vaccine have become a controversial issue in some communities, making it difficult for populations most at risk of infection to access treatment for this disease.

Henrietta Lacks: Cervical Cancer and the HPV Perspective

Time

Two-three class periods (60 minutes each)

Key Concepts

Cancer is related to the malfunctioning of the cell cycle through mutations to the DNA. Students will explore some of the ways that the cell cycle can be disrupted to cause cancer. Harald zur Hausen, using HeLa cells, discovered that cervical cancer was caused by Human Papillomavirus (HPV) which inserts its DNA into the host's DNA and disrupts the cell cycle. In this lesson, students will use the study of Henrietta Lacks and HeLa cells to understand cervical cancer and its causes. They will also investigate the pros and cons of the HPV vaccine and develop a social media campaign to educate the public.

Learning Objectives

In this lesson, students will:

- Discuss the history and legacy of Henrietta Lacks
- Understand the causes of cervical cancer and the role of Human Papillomavirus (HPV)
- Assess the pros and cons of the HPV Vaccine

Standards

HS-LS1-1. Construct an explanation based on evidence for how the structure of DNA determines the structure of proteins which carry out the essential functions of life through systems of specialized cells.

HS-ETS1-3. Evaluate a solution to a complex real-world problem based on prioritized criteria and trade-offs that account for a range of constraints, including cost, safety, reliability, and aesthetics as well as possible social, cultural, and environmental impacts.

Prerequisite Knowledge

Students should have a basic understanding that cancer is unchecked cell growth and the causes of cancer.

Materials and Handouts

For the Teacher:

- Lesson Powerpoint

For the Student:

- Post-It Notes
- Student Resource Sheet #1: Henrietta Lacks KWLQ
- Student Resource Sheet #2: Henrietta Lacks and HeLa Cells
- Student Resource Sheet #3: HPV Vaccine: Pros & Cons
- Student Resource Sheet #4: Study: Death Rate from Cervical Cancer Higher Than Thought

Activity 1

1. Show students the video that can be found at <https://www.youtube.com/watch?v=QOi976QXnJY> (Powerpoint Slide #2).
2. After viewing the video, divide students into small groups and display Powerpoint Slide #3. Groups should discuss the questions and record their answers on post-it notes.
3. Each group should be given an opportunity to share out their answers and place their post-it notes on the board. As a class, have students evaluate group responses and come to a consensus on the definition of cancer and its causes.
4. After the class comes to consensus, display Powerpoint Slide #4. Ask: How does their definition of cancer match with the one on the slide? Discuss. Make sure that students have a working knowledge of the other definitions before moving to the next activity.

Activity 2

1. Distribute Student Resource Sheet #1, Henrietta Lacks KWLQ. Have students work with a partner to complete the “What I Know” section of the graphic organizer. After a few minutes, introduce Henrietta Lacks to them using Powerpoint Slide #5. Allow students to add details to their graphic organizer. Tell students that the story of Henrietta Lacks has had a profound impact on the world of medicine. With their partners, students should complete the “Want to Know” section of the graphic organizer. Tell them that they are going to further examine Henrietta’s story by watching a video. The teacher can choose one of the videos to watch as a class or can divide the class and have each half watch a different video.

Video #1 - <https://www.youtube.com/watch?v=sXY6-wLesYY&feature=youtu.be>

- Video that describes Henrietta Lacks’ life and explains the cell line and the importance HeLa cells in research (Powerpoint Slide #6)

Video #2 - <https://ed.ted.com/lessons/the-immortal-cells-of-henrietta-lacks-robin-bulleri>

- TED talk video that describes Henrietta Lacks and HeLa cells and the specific type of cancer that she had that was caused by the HPV virus (Powerpoint Slide #7)

Depending on the ability level of students, the teacher might wish to assign one of the following articles to some of the students.

- Alexandria Del Carpio for Berkley Science Review, April 27, 2014
<http://berkeleysciencereview.com/article/good-bad-hela/>
- Mike Rogers from the Rolling Stone, March 26, 1976
<http://www.rollingstone.com/culture/features/the-double-edged-helix-19760325>

2. Explain to the students that as they watch the video or read their article, they should complete the “What I Learned” column of Student Resource Sheet #1. After the video or article, pair/group students who have viewed or read a different article. Have students review and add to their notes and discuss their thoughts on Henrietta Lacks, HPV, and HeLa cells. Do they still have questions about this topic? Have them record those questions in the last section of the KWLQ graphic organizer. How would they find those answers? Discuss.

Activity 3

1. Tell students that today, almost 70 years after Henrietta Lack’s death, cervical cancer is still a threat to women. Distribute Student Resource Sheet #3 “Study: Death Rate from Cervical Cancer Higher Than Thought.” Have students read and annotate the article, identifying the main points. Ask: How can cervical cancer be prevented? How is it treated? What method of prevention is recommended for children beginning at age 11 or 12?

2. Tell students that they are going to be examining the HPV vaccine in more detail. Show the video found at (https://www.youtube.com/watch?v=wQSTUlw8_1U). As they watch the video, they should take notes using Student Resource Sheet #3, “HPV Vaccine: Pros and Cons.” After watching the video, divide the class in half and assign the “Pro” side to one half and the “Con” side to the other. Students should discuss what they learned in the video. If time permits, you may wish to allow students time to further research their side of the argument and participate in a classroom debate.

Activity 4 – Conclusion

1. Display Powerpoint Slide #10. Allow students a few minutes to digest the information. Discuss what the term “recommended” means.
2. Display Powerpoint Slide #11. Ask: Why do you think that the vaccination rate is at 60% instead of 100%? (They may wish to revisit information from the previous lesson activity.) What could/should be done to increase the vaccination rates? Discuss as a class.
3. Break students into groups. Explain to them that they will be creating a social media campaign to raise more awareness about the importance of HPV vaccination. Student groups should decide what social media platform (Twitter, Facebook, Instagram, etc.) to use and what audience to target (Parents or teenagers). Once they have selected the platform and the audience, they should be encouraged to do the following:
 - Figure out how to best communicate a mix of statistics, quotes, images, ideas, questions, and links to information and resources.
 - Consider how to dispel misconceptions, reinforce existing knowledge, and explain the correct use of terminology.
 - Develop a strategy for what types of information to provide and when, in either a short, sharply defined period of time (like one week) or in the longer term (say, over the course of the semester).
 - Work on developing the approach and “voice” they will use to communicate their information and grab people’s attention.
 - Brainstorm how they will attract followers.

If possible, have the class actually create a Facebook page, Twitter account or the equivalent on another social media site and launch their social media campaign. If they do launch a real social media campaign, develop a schedule for updates to be posted and track the results.

Alternatively, have them create a paper version. If they do it within the school, consider posting their work in a public space, like the library, cafeteria or hallway, where other students can read (and respond to) the posts.

(Activity modified from (<https://learning.blogs.nytimes.com/2010/12/01/raising-awareness-developing-social-media-campaigns-about-h-i-v-and-aids/>))

Extension

- Using the article from Student Resource Sheet #3, students can examine the disparity in cancer rates between African American and white women. “Black women are dying of cervical cancer at twice the rate as white women in the United States and we need to put in place measures to reverse the trend.” Anne F. Rositch, Ph.D., MSPH. What might be some of the reasons for this disparity? Students can research this topic and develop a social media campaign to target this particular population.

Student Resource Sheet #1

Henrietta Lacks KWLQ

What I KNOW	What I WANT to Know	What I LEARNED	What new QUESTIONS do I have?

Student Resource Sheet #2

Henrietta Lacks and HeLa Cells

Henrietta Lacks was diagnosed with cervical cancer in 1951 at John Hopkins Hospital in Baltimore, Maryland. Cervical cancer is almost exclusively caused by infection of the Human Papillomavirus (HPV). HPV infects epithelial cells. These cells, which are organized in layers, cover the inside and outside surfaces of the body, including the skin, the throat, the genital tract, and the anus.

When there is an infection, viral DNA enters into the nucleus of the basal cells at the bottom of the epithelial layer. With time, as the infected cells mature and begin moving upward, new viral proteins will be produced. When the cells reach the outermost layer and die, new virus particles are released.

In around one infection out of ten, some viral DNA will be integrated into the basal cell's genome. It is at this point that the activity of two viral genes, called E6 and E7, start to interfere with cell functions that normally prevent excessive growth, helping the cell to grow in an uncontrolled manner and to avoid cell death.

(National Cancer Institute, cancer.gov)

Press Release Nobel Prize

Student Resource Sheet #3

HPV Vaccine: Pros and Cons

Pros	Cons

Student Resource Sheet #4

Study: Death Rate from Cervical Cancer Higher Than Thought, January 23, 2017

The death rate from [cervical cancer](#) in the U.S., is higher than previously thought, especially among African-American women and older women, according to a study by researchers at Johns Hopkins University. The study was published January 23 in [Cancer](#), a peer-reviewed journal of the American Cancer Society.

The researchers found that black women in the U.S., are dying from cervical cancer at a rate 77% higher than previously thought, and white women are dying at a rate 47% higher than previously thought. They arrived at the new numbers by excluding women who have had hysterectomies, which typically involve removal of the cervix — thereby eliminating the [risk of getting cervical cancer](#). They say their data provide a more accurate view of who is getting cervical cancer, which will help efforts to prevent it.

The researchers also found the disparity between black and white women increases with age. Black women age 85 and older had the highest death rate using the new calculation.

In 2017, an estimated 12,820 new cervical cancer cases are expected to be diagnosed in the U.S. and an estimated 4,210 women are expected to die from it to prevent it.

A Clearer Picture Of Disparity

The researchers got their data from the National Center for Health Statistics and from the Surveillance, Epidemiology, and End Results (SEER) national cancer registries. They looked at the rates of death from cervical cancer, and then recalculated the rates after removing those who had had a hysterectomy from the database numbers. Excluding these women makes a big difference because as many as 1 in 5 women have had a hysterectomy, according to the study. Black women are more likely than white women to have had hysterectomies, and at younger ages, in large part because they are more susceptible to fibroid tumors, which can lead to the surgery.

The study's calculations show that black women in the U.S., who have not had a hysterectomy are about as likely to die from cervical cancer as women in underdeveloped countries of sub-Saharan Africa.

The study was not designed to uncover the reasons for the disparities, although previous research suggests that black women are more likely than white women to have their cervical cancer caught at a later [stage of diagnosis](#) and may be more likely to receive [radiation](#) and less likely to receive [surgery](#) as part of their treatment. The study authors say future research should focus on investigating and overcoming factors that contribute to differences in death rates.

“While trends over time show that the racial disparities gap has been closing somewhat, these data emphasize that it should remain a priority area,” said Anne F. Rositch, Ph.D., MSPH. “Black women are dying of cervical cancer at twice the rate as white women in the United States and we need to put in place measures to reverse the trend.”

Most cervical cancers can be prevented or found early

Virtually all cervical cancers are caused by infection with certain types of the [human papillomavirus \(HPV\)](#). Following the [American Cancer Society guidelines](#) can help find cervical cancer early, and can also find pre-cancers, which can be treated to keep cervical cancer from forming.

- All women should begin cervical cancer screening at age 21.
- Women between the ages of 21 and 29 should have a Pap test every three years. They should not be tested for HPV unless it is needed after an abnormal Pap test result.
- Women between the ages of 30 and 65 should have both a [Pap test](#) and an HPV test every five years. This is the preferred approach, but it is also OK to have a Pap test alone every three years.

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- Women over age 65 who have had regular screenings with normal results should not be screened for cervical cancer. Women who have been diagnosed with cervical cancer or pre-cancer should continue to be screened according to the recommendations of their doctor.
 - Women who have had their uterus and cervix removed in a hysterectomy and have no history of cervical cancer or pre-cancer should not be screened.
 - Women who have had the HPV vaccine should still follow the screening recommendations for their age group.
 - Women who are at high risk for cervical cancer may need to be screened more often. Women at high risk might include those with HIV infection, organ transplant, or exposure to the drug DES. They should talk with their doctor or nurse.

Another way of preventing cervical cancer is to get vaccinated against HPV. But to get the most out of the HPV vaccine, it should be given at an early age. The American Cancer Society recommends that the vaccine series be started at age 11 or 12, although it can be given to girls and women up to age 26.

<https://www.cancer.org/latest-news/study-death-rate-from-cervical-cancer-higher-than-thought.html>