

A Gift Not Given: Henrietta Lack's Unwilling Contribution to Modern Medicine

In 1951, the Center for Disease Control (CDC) reported the deaths of more than 170,000 Black men and women within the United States of America.¹ Many were unknown outside of their immediate family, remembered as nothing more than a statistic. And the death of a 31 year old Black woman on October 4th of that same year seemed no different.² Her life was finite, her story one of a poor mother of five growing up in the Southern USA an all-too common, yet easily forgettable one. Her contributions extended no further than the household, her legacy set to be a loving wife and mother. For two decades, that is exactly how she remained, remembered only by those close to her.³ Unbeknownst to her family however, were the countless contributions her body had made in the quest towards modern medicine, and the lasting impact she would have within the field. Henrietta Lacks was born and died a nameless Black woman in the eyes of American healthcare, yet her cells have lived on, immortalized as one of medicine's greatest discoveries.

Henrietta Lacks was born August 1st, 1920 in Roanoke, Virginia.⁴ Though slavery had been abolished half a century prior, her family still felt its effects, struggling financially and with the longstanding racial environment of the South. Not an uncommon practice at the time,

¹ U.S. Department of Health, Education and Welfare, *Vital Statistics of the United States 1951*, 1954 (Accessed March 2, 2022); available from https://www.cdc.gov/nchs/data/vsus/VSUS_1951_2.pdf

² Biography, *Henrietta Lacks*, 2018 (accessed March 2, 2022); available from <https://www.biography.com/scientist/henrietta-lacks>

³ Rebecca Skloot, *The Immortal Life of Henrietta Lacks* (New York: Crown Publishers, 2010), chapter 1, para.14

⁴ (Skloot 2010, chapter 2, para.1)

Henrietta gave birth to her first son at 14, and was married with another child shortly after her 20th birthday. After learning of the rising economy upstate, Henrietta, her husband David, and their children moved to Turners Station in the hopes of starting a better life. The following years presented the couple with a vast array of challenges; welcoming three more children into their family, infidelity, a rapidly changing economy, and lingering racial tensions. However, they persevered, determined to make a life better than the one left behind.⁵

Like many Black folks living in the US at the time, Henrietta was cautious about seeing white medical professionals, and often put off doctors visits unless absolutely necessary. At the age of 28, she began complaining of pain and discomfort in her lower abdomen, but attributed it to the recent birth of her daughter, and then her preceding pregnancy. It was not until the pain remained after the birth of her fifth child Joe in 1950 that Henrietta recognized the severity of her health outweighed her concerns of seeing a white doctor. Her local doctor performed the initial exam, believing her pain to be caused by untreated syphilis, but referred her to the John Hopkins gynecology center when the test came back negative. On January 29th, 1951, two years after she initially complained of pain and discomfort, Henrietta traveled to East Baltimore to see Dr. Howard Jones and finally received a diagnosis. This was not her first time visiting John Hopkins, just three months prior she had gone in for her six week check-up after giving birth to Joe. All of her scans and tests had come back normal, and doctors could not explain the cause of her pain.⁶ This time was different however. Dr. Jones immediately recognized a tumor in Henrietta's uterus, and after running tests, confirmed that she had Type 1 Epidermoid Carcinoma.⁷ Though she had only consented to the testing of her cancer cells, Dr. Jones collected an extra tissue sample from

⁵ (Skloot 2010, chapter 2, para. 24-37)

⁶ (Skloot 2010, chapter 1, para. 4-13)

⁷ (Skloot 2010, chapter 3, para. 1)

the tumor, which he intended to pass along to his coworker, Dr. George Gey. Henrietta agreed to start radiation therapy as soon as possible, and her sessions were supervised by yet another doctor, Dr. Richard Wesley TeLinde. Not unlike Dr. Jones, TeLinde also nonconsensually collected tissue samples from Henrietta, also passing them along to Gey.⁸

Dr. Richard Gey was the head of Tissue Culture Research at John Hopkins, and had been experimenting with the creation of ‘immortal’ cells, with little success. The samples he had been collecting - all taken nonconsensually - had died less than 48 hours after being cultivated, and his goal seemed to be impossible. The samples taken from Henrietta however, gave Gey and his research team new hope, multiplying rapidly even past the expected 48 hour lifespan. Nicknamed HeLa, Gey began running tests and experiments on the samples, introducing them to various viruses, climate conditions, and radiation.⁹ As Henrietta’s cells fought back and continued to grow, so did she. Two weeks after her initial treatment appointment, Henrietta’s tumor began shrinking, and her pain had almost completely disappeared. Doctors thought she was on the path to recovery, beating the odds against her aggressive cancer. Unfortunately, it did not last long. A suspected gonorrhea infection sent Henrietta back into relapse, and her tumor began rapidly growing, and an inoperable mass was found not long after. On August 8th, 1951, Henrietta entered John Hopkins Medical Center for the last time, agreeing to hospice care until she passed. Less than a month later, a scan showed that her cancer had metastasized, with tumors across almost every organ. Henrietta Lacks died on October 4th, 1951, less than 10 months after receiving her diagnosis.¹⁰

⁸ (Skloot 2010, chapter 3, para. 13-15, 19)

⁹ (Skloot 2010, chapter 4, para. 2526-27)

¹⁰ (Skloot 2010, chapter 8, para. 1, 6, 11)

At the time, there were no legal or ethical frameworks for collecting tissue samples from living persons, meaning neither Henrietta nor her family were made aware that her cells had been collected and tested on. It was only upon death that consent was required to harvest organs or tissue for further testing. Knowing that her family would not consent to research purposes, Dr. Gey asked Henrietta's husband, Dave, if they could remove some of her organs to run tests that could possibly indicate if their children were at risk of being diagnosed with cancer in the future. Dave agreed, his lack of education and medical knowledge and grief over the loss of his wife allowing him to be manipulated. In the 10 months that Henrietta received treatment and care in John Hopkins, she was not once informed that her tissue cells had been removed, let alone been the focus of international attention.¹¹

Throughout the course of Henrietta's treatment and eventual end-of-life care, Dr. Gey and his team ran countless tests and experiments on her tissue samples, and he appeared on national television that April to discuss the results of his studies. Research departments from across the world began reaching out, asking for their own samples, so that they too could run experiments and tests.¹²

In 1953, the United States government began using HeLa cells to study hemorrhagic fever, which had previously been a danger to military teams overseas.¹³

In October 1952, just a year after Henrietta's death, the National Foundation for Infantile Paralysis (NFIP), reached out to Gey and his team to pursue research into HeLa cells as the basis

¹¹ (Skloot 2010, chapter 12, para. 1-3)

¹² (Skloot 2010, chapter 7, para. 5-7)

¹³ (Skloot 2010, chapter 7, para. 1, 6-7)

of a possible polio vaccine. Their research proved to be promising, and a vaccine was developed and introduced to the general public by 1955.¹⁴

Various medical facilities used tissue samples to gain a better understanding of how human cells could be frozen without damaging or harming them, which in turn led to the ability to clone cells, and in-vitro fertilization procedures. In 1955, two scientists, Joe Tijo and Albert Levan from the National Institute of Health, used HeLa cells to confirm that humans had 46 chromosomes, not 48 as previously thought.¹⁵

In 1956, the ‘immortality’ of HeLa cells allowed scientists to examine how X-rays affect cell reproduction, leading to the development of safer imaging practices. That same year, researchers used the samples to develop testing practices that confirmed if cells within the body were cancerous or not.¹⁶

In 1964, amidst the US-USSR space race, HeLa cells were sent into space, to research effects of atmospheric change and radiation on the human body. The cells were also used in tests to examine the effectiveness of Hydroxyurea, a treatment designed to fight sickle-cell anemia and similar blood cancers.¹⁷

In 1985, the cells were used to give scientists a better understanding of how the Human Papilloma Virus (HPV) can lead to cervical cancer, and in 2008 Dr. Harald zur Hausen won a Nobel Prize for his work in developing the HPV vaccine.¹⁸

¹⁴ National Institutes of Health, *Significant Research Advances Enabled By HeLa Cells* (accessed April 4, 2022); available from <https://osp.od.nih.gov/scientific-sharing/hela-cells-timeline/>

¹⁵ Chapter 13

¹⁶ (*Significant Research Advances Enabled By HeLa Cells*)

¹⁷ (*Significant Research Advances Enabled By HeLa Cells*)

¹⁸ Leah Samuel, *5 Important Ways Henrietta Lacks Changed Medical Science*, 2017 (accessed April 4, 2022); available from <https://www.statnews.com/2017/04/14/henrietta-lacks-hela-cells-science/>

In 1988 - the peak of the AIDs crisis - it was shown that HeLa cells responded much slower to AIDs infections, which eventually led to the development of drugs that limited and prevented the spread of HIV.¹⁹

Even into the mid-21st century, HeLa cells have continued to contribute to medical discoveries, and it is estimated that their role in research has brought in an annual \$35Billion to research firms across the world.²⁰

The decades following Dr. Gey's advancements were filled with radio and television appearances, guest appearances in medical journals, and hundreds of thousands of dollars in endorsements for both Gey and the John Hopkins Center. On November 2nd, 1953, almost 3 years after Henrietta's passing, The Minneapolis Star published an article commemorating HeLa cells and their contributions, making the historic decision to include the name of the woman to whom the cells truly belonged. Although they misprinted her name, this publication was the first to draw attention to the coerced anonymity that Henrietta Lack had been subjected to over the years. Once the public learned that there was a woman behind HeLa cells, finding her true identity became a race. Countless news agencies contacted Dr. Gey for interviews, yet the lack of patient confidentiality laws meant he held the right whether to release her name or not. While her family remained blind to the ways in which Henrietta's cells were changing the world, so did the hundreds of researchers, laboratory hands, and medical personnel that had capitalized on HeLa's abilities.²¹ It was not until the mid-1980s that anyone from the Lack family became aware, after

¹⁹ (*Significant Research Advances Enabled By HeLa Cells*)

²⁰ Becky Upham, *The Estate of Henrietta Lacks Sues Biotech Company for Selling 'Stolen' Cells*, 2021 (accessed March 9, 2022); available from <https://www.everydayhealth.com/public-health/the-estate-of-henrietta-lacks-sues-biotech-company-for-selling-stolen-cells/#:~:text=Hela%20cells%20and%20cells%20with,35%20billion%20dollars%20a%20year.>

²¹ (Skloot 2010, chapter 14)

discovering that John Hopkins had published Henrietta's full medical records and genome sequence to the public. After inquiring about the full extent and impact of HeLa cells, the Lack family discovered that although it was Henrietta's cells that had amassed billions of dollars in research and advancement funds.²² Gey had chosen to release his samples as general scientific property, meaning the family could neither stake a claim for ownership, or receive any financial benefits.²³ The turn of the 21st century has seen significant improvements concerning the recognition of Henrietta and her tissue cells, yet she remains laid to rest at an unmarked grave in Turner Station, and her descendants still live in extreme poverty and wealth instability.

Henrietta's cancer cells have carved a new path for medical research, providing scientists with abilities to create numerous vaccines, gain a better understanding of human cell cycles, and even find breakthroughs for global catastrophes such as the HIV/AIDs crisis and the COVID-19 pandemic. However, it is not these medical miracles alone that have granted her the legacy of being immortal. Her story - once hidden under stacks of paperwork on a desk in John Hopkins - now acts as a framework for the way in which patient consent and confidentiality is handled, while also inspiring activist groups to bring attention to medical advancements made possible through coercive and non-consensual practices.

Established in 2013 by Rebecca Skloot, the Henrietta Lacks Foundation serves two purposes; immortalize Henrietta's life, and bring attention to and reparations for victims of medical experimentation in the United States.²⁴

²²Van Smith, "Wonder Woman: The Life, Death, and After Life of Henrietta Lacks, Unwitting Heroine of Modern Medical Science", *Baltimore City Paper*, April 17, 2002.

²³ (Skloot 2010, chapter 13, para. 41)

²⁴ The Henrietta Lacks Foundation, *About*, 2010 (accessed March 18, 2022); available from <http://henrietalacksfoundation.org/>

In the 1930s, Black men in Macon County, Alabama, were recruited by medical professionals to partake in a study to research how syphilis infects the body, and its reaction to various treatment procedures. However, the individuals apart of the experiment were never informed that they were being injected with syphilis bacteria, but instead were under the impression they were being treated for a variety of possible health conditions. Over the next ten years, scientists learned that syphilis was quickly and easily cured with penicillin, yet felt the Black men they were studying were not worthy enough to be treated. Of the 400 men infected with syphilis, 130 died from complications, and dozens had unknowingly infected their wives and children, leaving them with lifetimes of health problems.²⁵

Beginning in the 1930s and peaking by the 1970s, doctors in many southern US states took on the practice of forcefully sterilizing Black women, many of which had gone in for a routine appendectomy procedure. Not unlike the Tuskegee Syphilis Study, the doctors performing the sterilizations felt that Black women were unfit to be proper mothers, and felt society would benefit by removing or damaging the reproductive organs of their Black patients. Initially presented as a way to prevent mentally disabled women from bearing a child if raped, the procedure quickly warped into one of racial eugenics. Over the span of 40 years, it is estimated that over 8,000 Black women were sterilized without their knowledge or consent.²⁶

The threat of a nuclear arms race between the USA and USSR following the end of WW11 could not even deter race-based medical experimentation. Between 1944 and 1971, as the world sat at the edge of possible annihilation, the US Department of Defense enlisted a number

²⁵ 40 Years of Human Experimentation in America: The Tuskegee Study, *McGill*, 2019 (accessed April 1, 2022); available from <https://www.mcgill.ca/oss/article/history/40-years-human-experimentation-america-tuskegee-study>

²⁶ Lisa Ko, *Unwanted Sterilization and Eugenics Programs in the United States*, 2016 (accessed April 1, 2022); available from <https://www.pbs.org/independentlens/blog/unwanted-sterilization-and-eugenics-programs-in-the-united-states/>

of doctors and hospital staff to aid in testing the effects of nuclear radiation on the human body. Cancer patients attending radiation therapy were unknowingly being exposed to varying levels of nuclear radiation, and observed for the emergence of possible side-effects. At the University of Cincinnati, 88 cancer patients were intentionally exposed to radiation dosages, more than half of which were African American.²⁷

The Henrietta Lacks Foundation has dedicated its mission to aiding the victims and family members of human experimentation across the US, awarding grants and legal support for those who wish to pursue financial reparations. Working alongside victims of the Tuskegee Syphilis Study, Mississippi Appendectomies, and Human Radiation Experiments, the Foundation has awarded more than 90 grants for physical and mental health treatments, and helped countless individuals bring awareness to their stories.²⁸

On December 18th, 2020, the U.S. Senate introduced and passed a landmark piece of medical legislation, to investigate the racial inequalities still present in cancer research. The Henrietta Lacks Enhancing Cancer Research Act aims to ensure clinical trials for new cancer treatments include proportional representation of Black, Hispanic, and Indigenous peoples, and highlights the staggering cancer diagnosis rates within non-white communities.²⁹ Two years prior to the passing of this Act, the U.S. Department of Health and Human Services revised the 1981 Common Rule, the standard of ethics for the treatment and handling of human test subjects. One of the key revisions made involved the means of acquiring patient consent, mandating that any language used on behalf of medical professionals must be given in plain, easily understood

²⁷U.S. Department of Energy, *Human Radiation Experiments*, 1995 (accessed April 5, 2022); available from <https://www.osti.gov/opennet/servlets/purl/16141769/16141769.pdf>

²⁸ (*The Henrietta Lacks Foundation*, 2010)

²⁹ U.S. Congress, *H.R. 1966 - Henrietta Lacks Enhancing Cancer Research Act of 2019*, 2019 (accessed April 18, 2022); available from <https://www.congress.gov/bill/116th-congress/house-bill/1966/text>

terms, and allow patients the opportunity to ask questions and air concerns. It also requires patients be informed that samples collected hold the possibility of producing commercial profit, a percentage of which the patient may own the rights to. Most notable to the life of Henrietta Lacks involves giving consent for access to one's complete genome sequence for collection and research purposes. Henrietta was robbed of the opportunity to give consent for her tissue samples, and was subsequently exploited when her human genome sequence was released to the public.³⁰

For more than 30 years, Henrietta Lacks remained just another statistic, a lone figure pointing to the ways in which medicine continued to fail Black men and women in the United States of America. But as she remained anonymous, her tissue cells - extracted under the guise of treatment - became an internationally recognized name. Her HeLa cells made strides in the field of medical research, aiding in advancements still used almost a century later. Scientists like Gey, Jones, and TeLinde found ways to monopolize on their actions, bringing in millions of dollars to the John Hopkins Medical Center. At the same time, Henrietta's family remained poverty-stricken and unaware of the ways in which their beloved was changing the world. The story of Henrietta Lacks and her immortal cells point to the arcane history of medical racism, not just within the US, but across the world. For hundreds of years, non-white peoples have been victimized through nonconsensual procedures, experimentation, and testing environments. Many of the taken-for-granted healthcare tools used today stem from the abuse and exploitation of Black and Indigenous communities at the hands of white medical professionals, and continue to remain hidden by those who benefited. Henrietta is a symbol of the hardships experienced by

³⁰ Office for Human Research Protections, *Revised Common Rule*, 2017 (accessed April 18, 2022); available from <https://www.hhs.gov/ohrp/regulations-and-policy/regulations/finalized-revisions-common-rule/index.html>

African Americans since the onset of slavery and racial discrimination, and acts as a beacon of hope for other victims and family members internationally. It now has become better understood and accepted that America itself was built on the back of African slaves, and many still assume the abolition of slavery also abolished anti-Black racism. The immortality of Henrietta's cells, and the recognition that Black bodies are the face of medical advancements cannot be ignored, or forgotten. To commemorate Henrietta would be to commemorate the countless Black lives lost at the hands of white medicine, and push even closer to true acts of reparations and societal growth everywhere.

Works Cited

- Biography, *Henrietta Lacks*, 2018. Accessed March 2, 2022. Available from <https://www.biography.com/scientist/henrietta-lacks>
- Ko, L. *Unwanted Sterilization and Eugenics Programs in the United States*, 2016. Accessed April 1, 2022. Available from <https://www.pbs.org/independentlens/blog/unwanted-sterilization-and-eugenics-programs-in-the-united-states/>
- National Institutes of Health, *Significant Research Advances Enabled By HeLa Cells*. Accessed April 4, 2022. Available from <https://osp.od.nih.gov/scientific-sharing/hela-cells-timeline/>
- Office for Human Research Protections, *Revised Common Rule*, 2017. Accessed April 18, 2022. Available from <https://www.hhs.gov/ohrp/regulations-and-policy/regulations/finalized-revisions-common-rule/index.html>
- Samuel, L. *5 Important Ways Henrietta Lacks Changed Medical Science*, 2017. Accessed April 4, 2022. Available from <https://www.statnews.com/2017/04/14/henrietta-lacks-hela-cells-science/>
- Skloot, R. *The Immortal Life of Henrietta Lacks*. New York: Crown Publishers, 2010.
- Smith, V. “Wonder Woman: The Life, Death, and After Life of Henrietta Lacks, Unwitting Heroine of Modern Medical Science”, *Baltimore City Paper*, April 17, 2002.
- The Henrietta Lacks Foundation, *About*, 2010. Accessed March 18, 2022. Available from <http://henrietalacksfoundation.org/>
- Upham, B. *The Estate of Henrietta Lacks Sues Biotech Company for Selling ‘Stolen’ Cells*, 2021. Accessed March 9, 2022. Available from <https://www.everydayhealth.com/public-health/the-estate-of-henrietta-lacks-sues-biotech-company-for-selling-stolen-cells/#:~:text=Hela%20cells%20and%20cells%20with,35%20billion%20dollars%20a%20year.>
- U.S. Congress, *H.R. 1966 - Henrietta Lacks Enhancing Cancer Research Act of 2019*, 2019.

Accessed April 18, 2022. Available from
<https://www.congress.gov/bill/116th-congress/house-bill/1966/text>

U.S. Department of Energy, *Human Radiation Experiments*, 1995. Accessed April 5, 2022.
Available from <https://www.osti.gov/opennet/servlets/purl/16141769/16141769.pdf>

U.S. Department of Health, Education and Welfare, *Vital Statistics of the United States 1951*,
1954. Accessed March 2, 2022. Available from
https://www.cdc.gov/nchs/data/vsus/VSUS_1951_2.pdf

40 Years of Human Experimentation in America: The Tuskegee Study, *McGill*, 2019. Accessed
April 1, 2022. Available from
<https://www.mcgill.ca/oss/article/history/40-years-human-experimentation-america-tuskegee-study>