

### Case Study A: Henrietta Lacks and HeLa Cells

Henrietta Lacks died when she was 31 years old in a segregated hospital ward for “coloreds” in Baltimore, Maryland on October 4, 1951. Lacks was a poor, black woman from an uneducated family who had worked in the tobacco fields in Virginia almost all of her life. She married young and had five children.

Soon after the birth of her youngest child in 1950, Henrietta discovered a lump in her body. A doctor at a free clinic ward for colored people examined her lump and the diagnosis was **cervical cancer**. The doctor performed a routine medical procedure to collect **tissue samples** from her cancerous tumor. At the time, it was common for doctors to send tissue samples to research facilities so that cells could be studied to learn more about many diseases. The rules for getting **informed consent** from patients were much less strict than they are today. Henrietta’s doctors did not inform her about what they were doing or get her permission for the tissue collection, though they did get consent from her husband to perform an **autopsy** after her death.

On the same day that Henrietta passed away, Dr. George Gey [pronounced “guy”], a leading researcher who had been trying to establish the successful growth of a stable **human cell line**, appeared on television to present his contribution to the fight against cancer. Dr. Gey introduced to the world the first successfully grown human cell line, which he termed “HeLa” in honor of the human patient who had unknowingly donated to the cause— Henrietta Lacks.

As Dr. Gey was presenting his discovery, scientists all over the world were being given HeLa cells for free to conduct their own studies. The HeLa cell line became an essential resource for medical research in many labs worldwide. Soon, many companies began mass producing HeLa cells for commercial research use, reaping millions of dollars in profits that would never have been possible without Henrietta’s cells. HeLa cells have since been used in many ways, including testing vaccines, learning about genetics, research into cancer and AIDS, and developing drugs. It took decades, and the help of a journalist, for the family to learn what had happened to their mother’s cells.

Henrietta was buried in an unmarked grave for almost 60 years, until 2010. Her headstone has now been marked with her name and an inscription that reads “In loving memory of a phenomenal woman, wife, and mother who touched the lives of many. Here lies Henrietta Lacks (HeLa). Her immortal cells will continue to help mankind forever.”

Henrietta’s family never received any part of the billions of dollars that HeLa cells brought (and continue to bring) to many companies. In fact, since Henrietta was never informed that her tissue had been collected, for more than 20 years after her death, her family was unaware of the robust industry Henrietta’s cells helped launch or her “immortal” status.

The Lacks’ family and children are still economically disadvantaged. Many of Henrietta’s descendants can’t afford health insurance or treatments that have been made possible by direct work with the HeLa cell line. Deborah, the fourth of Lacks’ children, describes the situation: “Truth be told, I cannot get mad at science, because it helps people live and I’d be a mess without it. But I won’t lie. I would like some health insurance so I don’t got to pay all that money every month for drugs my mother’s cells probably helped make.”

*This summary is based on a true story. Please see the Sources section for reference information.*

*Contributed by Myra Amon, Redmond High School, Redmond, WA.*

**Autopsy:** An examination conducted on a dead body to determine the cause of death.

**Cervical cancer:** Cancer of the cervix, which is the lower, narrow end of the uterus.

**Human cell line:** A continuously dividing set of cells used in medical research that are derived from a single human cell.

**Informed consent:** A process that outlines required elements of research participation, including its risks and potential benefits, to help someone decide whether to participate. An informed consent form is used to convey essential information and is signed by the participant if he or she decides to join the study.

**Tissue sample:** Bodily fluids (e.g., blood or saliva) or tissue (e.g., cells, skin, bone, or muscle) for use in research.

### Case Study B: The Havasupai Indians

The Havasupai Indian tribe lives in the state of Arizona, deep in the Grand Canyon, relatively isolated from the rest of U.S. society. The tribe's language, called Pai, is spoken by all of its approximately 639 members. Only a few members of the tribe have graduated from an English-speaking high school. Unemployment is very high in the community and income is mostly dependent on seasonal tourism. To access medical facilities, tribal members must either hike for miles on a steep trail or leave the canyon via horse or helicopter.

In the 1960s, the tribe began seeing a very high **incidence** of **Type II Diabetes** among their members. As a result, many of the members suffered poor health, and some needed to have limbs amputated to treat the disease. In 1989, members of the tribe contacted researchers at Arizona State University (ASU) to figure out how to control the disease and treat members of the tribe.

Researchers had already established that a neighboring tribe, the Pima Indians, had a genetic link to diabetes. The researchers sought to investigate whether the Havasupai had a similar genetic link to the condition. The researchers from ASU received money in 1990 from the university to carry out the investigation. From 1990 to 1994, many tribe members were recruited for the study. To participate, the members signed a general consent form that stated the research they would be participating in would "study the causes of behavioral/medical disorders." The Havasupai research subjects provided blood samples. In turn, the tribe received limited medical care.

In 1991, the research study yielded a paper that showed that there was no direct evidence to link the tribe's genes to diabetes.

After the initial study was conducted, researchers continued to use the Havasupai's blood for research on **schizophrenia**, **inbreeding**, and patterns of human migration. The migration research is notable because the Havasupai never agreed to the use of tribal members' blood for research that might contradict the tribe's traditional **stories of origin**. The tribe became aware of this additional research in 2003, when one of the tribe members was invited to a talk at ASU where a doctoral student presented information from a study that used Havasupai blood samples. Carletta Tilousi, a tribe member who attended the ASU presentation, remarked, "I'm not against scientific research. I just want it to be done right. They used our blood for all these studies, people got degrees and grants, and they never asked our permission."

The tribe members who contributed blood samples for research purposes did not know that their blood was being used to study other conditions in addition to diabetes. The Havasupai tribe sued ASU and received \$700,000, several forms of additional support and resources for the tribe, and in 2010, the return of all their remaining blood samples.

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*Contributed by Myra Arnone, Redmond High School, Redmond, WA.*

**Type II Diabetes:** A chronic medical condition that affects how the body metabolizes sugar (glucose).

Type II Diabetes typically begins in adulthood and patients are not usually dependent on the use of insulin to control their sugar levels.

**Inbreeding:** When closely related people within an isolated group have children together, generation after generation.

**Incidence:** The percentage of newly diagnosed cases of a disease in a population.

**Schizophrenia:** A mental illness resulting in greatly impaired thinking, emotional responses, and behaviors.

**Stories of origin:** Stories that recount how something (or a people) came into being.

# STUDENT HANDOUT 1.1c

## The Tuskegee Syphilis Study

### Case Study C: The Tuskegee Syphilis Study

(Formally known as the U.S. Public Health Service Tuskegee Study of Untreated Syphilis)

From 1932 to 1972, the U.S. government conducted a study that focused on understanding the long-term effects of untreated syphilis, a sexually transmitted disease caused by bacteria. The original intent of the study was to show that the disease was “potentially...the same in African Americans and Caucasians.” The government claimed it wanted to study the effects of the disease so that it could develop programs to help treat syphilis in the local community.

The Tuskegee Syphilis Study, named after a college for black people called the Tuskegee Institute, took place in Macon County, Alabama. The study involved the active recruitment of poor, black, male sharecroppers. The researchers conducting the study told the men that they would be treated for “bad blood,” a term that was used in the local community to describe the symptoms of syphilitic disease—fatigue, fever, sores, and muscle aches.

The study, which was supposed to last up to nine months, continued for more than 40 years. Initially the study was approved by the Alabama state government with the expectation that the men would be treated for the disease. Researchers treated the men with the standard use of mercury and bismuth. These highly toxic remedies were sometimes fatal, and were only slightly effective since the cure rate was less than 30 percent and the treatment lasted several months.

Of the 600 men who enrolled and who consented, 399 men had syphilis and 201 did not have the disease. Although the men gave their consent, they were never informed about the research itself or that some of them actually had syphilis. In exchange for their cooperation, the men were promised free medical care, free meals, free travel to and from the clinics, and insurance for burials so that their families would not need to worry about the cost of their deaths.

In 1947, **penicillin** became available and was widely distributed as a highly effective treatment for syphilis; it became the standard of medical care for this disease. Although the researchers were aware that penicillin was effective against syphilis, they wanted to observe the consequences of the disease over time. The infected men in the study were never made aware of nor offered penicillin treatment.

In 1972, the study ended when a reporter wrote about the research in *The New York Times*. An advisory committee was formed to look into the study and strongly advised the researchers to stop the study. The men and their families received \$10 million in a settlement, and received healthcare for their wives and children. More than 100 men in the study died from syphilis-related complications, and some of the patients’ wives and children also contracted syphilis, which is sexually transmitted and can be passed to the fetus during pregnancy. The patients and their families did not receive a formal public apology from the U.S. government until President Bill Clinton apologized in 1997.

*This summary is based on a true story. Please see the Sources section for reference information.*

*Contributed by Myra Arnone, Redmond High School, Redmond, WA.*

**Penicillin:** An antibiotic drug made from penicillium mold (or produced synthetically) used to treat infections and diseases.

**Syphilis:** A sexually transmitted disease caused by bacteria, which can cause skin lesions. Left untreated, syphilis can cause inflammation, meningitis, and other central nervous system damage, as well as cardiovascular damage. Syphilis can remain in the body undetected for many years (latency) and symptoms can appear more than 40 years later.

### Case Study D: The Willowbrook Study

Warren was the fourth child and first boy born to a wealthy New York family in the 1950s. He was well loved by his sisters and parents. By the age of two it became obvious that Warren was different. When he was finally diagnosed as “profoundly retarded,” in the terms used at that time, his parents, who were unable to care for him, put him into one of the best care homes in New York. The family eventually faced financial problems and Warren was moved to Willowbrook State Hospital.

Willowbrook was opened in 1947 as a place to take care of New York’s mentally disabled population. Most patients were sent there as children when family doctors recommended that they needed more care than families could provide. The institution was plagued with **hepatitis** outbreaks throughout its first decade of operation. Recent estimates show that nearly 50% of patients living at Willowbrook in its early years of operation contracted hepatitis.

When the study began in the mid-1950s, the distinction between the various types of hepatitis was not known. The conditions at Willowbrook led Dr. Saul Krugman and Dr. Robert McCollum to believe that it would be an ideal place to study hepatitis to discover a possible cure for the disease. This could benefit both current and future children residing at Willowbrook. Letters describing the study were sent to parents of Willowbrook patients, asking permission for their children to participate. The short letter described how some patients would receive **antibodies** called gamma globulins that researchers hoped would provide long-term protection against hepatitis. Parents could tour an improved residential hospital wing set aside especially for study participants, meet with research staff, and ask questions about the study. Only children whose parents signed the permission form could participate in the study.

The study included two groups. The first included patients such as Warren who had been living at Willowbrook for some time, and were likely to get hepatitis whether they were in the study or not. The second group included patients who were essentially healthy and were newly admitted to Willowbrook. Warren’s group had two categories: children who received the antibodies, and children who did not. The healthy children who were new arrivals at Willowbrook all received the antibodies. During the study, some of the children unknowingly were deliberately infected with hepatitis by consuming the live virus, which was extracted from the feces of infected children. Some children were not infected at all. The children who were purposefully infected in the study tended to have milder reactions than children who contracted hepatitis naturally from other children in the hospital. A public outcry ultimately closed the study in the 1970s.

Warren was one of the last to leave Willowbrook when the facility closed in 1987. He now lives in a special care home where his sister communicates with him on a regular basis.

The Willowbrook Study showed that hepatitis can be divided into multiple types, which has allowed doctors to specify the type of treatment that is appropriate, and has led to a reduction in hepatitis outbreaks.

*This summary is based on a true story. Please see the Sources section for reference information.*

*Contributed by Erin Larson, Federal Way School District, Federal Way, WA.*

**Hepatitis:** Inflammation of the liver caused most frequently by viruses.

**Antibody:** A substance made by the body as an immune response that attacks and destroys foreign agents, such as viruses and bacteria.

# STUDENT HANDOUT 1.2

## Guiding Questions for Historical Case Studies

Name \_\_\_\_\_ Date \_\_\_\_\_ Period \_\_\_\_\_

Complete the following chart with your group after you read through your case study. Record information from the other case studies presented by other groups in your notebook.

	CASE STUDY:
1. What good came out of the research? What was the importance of the study?	
2. What things were not fair or are questionable about the research or its process?	
3. Who was involved in the case? Directly? Indirectly?	
4. Was everyone involved fully aware of and did they agree to be part of all aspects of the research?	
5. What was society's role in the case?	
6. How did social issues (e.g., poverty, education, religion) influence the case?	
7. What core values were in conflict in this case?	