

Name: \_\_\_\_\_

Date: \_\_\_\_\_

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Weekly Reading HW

HW Wk \_\_\_\_\_

*Directions: Read and annotate the passage below. Then answer the questions.*

### A Family Consents to a Medical Gift, 62 Year Later

Henrietta Lacks was only 31 when she died of cervical cancer in 1951 in Baltimore. Not long before her death, doctors removed some of her tumor cells. They later discovered that the cells could thrive in a lab, a feat no human cells had achieved before. Soon the cells, called HeLa cells, were being shipped to laboratories around the world. In the 62 years since, her cells have been the subject of more than 74,000 studies, many of which have yielded profound insights into cell biology, vaccines, and cancer. But Henrietta Lacks, who was poor, black, and uneducated, never consented to her cells being studied. Now, the National Institutes of Health (NIH) has come to an agreement with the Lacks family to grant them some control over how Henrietta Lacks's genome (entire set of DNA) is used.

The agreement is a milestone but also draws attention to a dearth of policies to balance the benefits of genome research with the privacy of people whose genomes are studied. Ms. Lacks's family did not learn that their mother's cells were being used in research, until 1973, when a scientist called to ask for blood samples to study the genes her children had inherited from her. Family members tried to find out more information but they were largely ignored for years.

In the meantime, scientists in Europe published the genome of HeLa cells, making it publicly available for downloading. Another study at the University of Washington was about to be published in *Nature*. The Lacks family was made aware of neither project. The NIH now acknowledges that they should have contacted the Lacks family when the family raised its objections. The European researchers took down their public data, and the publication of the University of Washington paper was stopped. "The biggest concern was privacy — what information was actually going to be out there about our grandmother, and in effect, us," said Ms. Lacks-Whye, one of Henrietta Lacks's grandchildren.

The Lacks family and the NIH settled on an agreement: the data from both studies would be stored in the NIH's database. Researchers who want to use the data can apply for access and will have to submit annual reports about their research. A HeLa Genome Data Access group, including two members from the Lacks family, will review the applications. With this agreement in place, the University of Washington researchers were then able to publish their results.

1. (RST.9-10.1) According to the passage, what was so special about Henrietta Lacks's cells?
  - a. Her cells were the first cervical cancer cells that scientists had seen.
  - b. Her cells were able to survive transport to laboratories around the world.
  - c. Her cells were the first human cells to be grown in a laboratory.
  - d. Her cells were the first human cancer cells to be studied in a woman.

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2. (RST.9-10.2) The reader can conclude from the passage that Henrietta Lacks's family:
- a. Is disappointed that the University of Washington was able to publish their study.
  - b. Is satisfied that they now have a say in how HeLa cells are used in research.
  - c. Is angry that Henrietta Lacks gave her cells to her doctor without telling them.
  - d. Is pleased that so many scientists want to study the HeLa genome.
3. (RST.9-10.4) As it is used in the passage, the term *dearth* means:
- a. Abundance
  - b. Termination
  - c. Lack
  - d. Restriction
4. (RST.9-10.1) How many years had scientists been using HeLa cells for research before the family found out about their use?
- a. 51 years
  - b. 22 years
  - c. 62 years
  - d. 73 years
5. (RST.9-10.1) How did the Lacks family first learn that HeLa cells were being used by scientists?

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6. (RST.9-10.1) Describe the agreement that was reached between the Lacks family and the NIH.

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*Adapted from the article, "A Family Consents to a Medical Gift, 62 Years Later" by Carl Zimmer for The New York Times, on August 7, 2013.*