The Immortal Life of Henrietta Lacks STUDY GUIDE

In 1951 a poor young black woman, Henrietta Lacks, was diagnosed with cervical cancer at John Hopkins Hospital. Cells taken from her during that exam were used – without her knowledge – to develop the first immortal cell line. The cells, called HeLa, became one of the most important tools in medical research, vital for developing the polio vaccine, cloning, gene mapping, and more, but Henrietta Lacks, the person who was the sources of these cells, was virtually unknown, and her family was never informed about what had been achieved using her cells. Although their mother’s cells have been bought and sold by the billions the Lacks family have received nothing from those cell lines, and cannot even afford health insurance today. This book tells the stories of HeLa and of Henrietta Lacks and her descendants, especially her daughter, Deborah, who was consumed with questions about her mother she never knew. At the same time it traces the history of cell research and examines the ethical and legal issues raised by this research.

About the Author – Rebecca Skloot is an award-winning science writer, with a B.S. in biological sciences and an MFA in creative writing. She first heard about Henrietta Lacks and HeLa in a community college biology class. As she continued her studies she became fixated on the idea of telling Henrietta’s. She spent over a decade researching and writing the story.

Prologue: The Woman in the Photograph
1. What are your thoughts about learning more about the story of Henrietta Lacks?

Deborah’s Voice
1. What is your impression of Deborah, given this brief excerpt?

Chapter 1: The Exam (1951)
1. Is Henrietta Lacks’ able to understand and make informed decisions about her treatment at the clinic? Explain.
2. How would you describe Henrietta’s attitudes toward medical care?

Chapter 2: Clover (1920-1942)
1. What do you think of the description of Henrietta’s childhood years in Clover?

Chapter 3: Diagnosis and Treatment (1951)
1. What is your impression of medical understanding and treatment of cervical cancer of 1951?
2. Do you believe that Dr. TeLinde’s research was important and justified? Explain.
3. Do you think the Operation Permit that Henrietta signed gave the hospital the right to take her tissue for research purposes? Do you think Henrietta understand what she was signing?

Chapter 4: The Birth of HeLa (1951)
1. Why did Dr. Gey give samples of the HeLa cells to his colleagues?
2. What are your thoughts of the issue of sterile procedures in the lab, based on the description?

Chapter 5: Blackness Be Spreadin All Inside (1951)
1. How well do you think Henrietta understood her illness? Her treatment?

Chapter 6: Lady’s on the Phone (1999)
1. Why did Dr. Pattillo ask Rebecca Skloot what she knew about African Americans and science before deciding to let her contact the Lacks family?
2. How well do you think the Lacks family understood what had been done with Henrietta’s cells?

Study Guide writer – Liane Bryson teaches at San Diego State University.
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Chapter 7: The Death and Life of Cell Culture
1. Would it be possible for scientists to make claims like Alexis Carrel’s today and have them as widely accepted by other scientists, the media, and the public?
2. Why was the development of an “immortal” cell line like HeLa potentially so important to medical research?

Chapter 8: A Miserable Specimen (1951)
1. How did the elevated status of doctors in the 1950s affect the quality of the medical care they gave to their patients, both positively and negatively?
2. What is your impression of the medical care Henrietta received?

Chapter 9: Turner Station (1999)
1. What is your impression of Turner Station and the people who live there?

Chapter 10: The Other Side of the Tracks (1999)
1. What do you think of Cootie’s understanding of HeLa cells?
2. What is your impression of Clover?

Chapter 11: The Devil of Pain Itself (1951)
1. What is your reaction to the medical decisions regarding blood transfusions and discontinuing cancer treatments for Henrietta Lacks?

Chapter 12: The Storm (1951)
1. Why was it a surprise for Dr. Gey’s assistant to suddenly think of Henrietta as a person when she saw the chipped toenail polish? Do doctors and scientists tend to see patients as bodies or specimens rather than as people?

Chapter 13: The HeLa Factory (1951-1953)
1. Why is standardization of procedures considered so critical to scientific research? How can that standardization also limit the growth of research?
2. Did Microbiological Association have the right to begin growing and selling HeLa cells, even though they had played no role in developing them?

Chapter 14: Helen Lane (1953-1954)
1. Why did George Gey decline to identify Henrietta Lacks for journalists?
2. Should Gey have informed the Lacks family about the origins of HeLa? Why or Why not?

Chapter 15: Too Young to Remember (1951-1965)
1. Briefly explain the conditions the Lacks children grew up in after their mother died – Sonny (4), Deborah (2) and Joe (1).

Chapter 16: Spending Eternity in the Same Place (1999)
1. Why did Cliff bring Skloot to the family cemetery?

Chapter 17: Illegal, Immoral and Deplorable (1954-1966)
1. What were the justifications given for Southam’s failure to inform his subjects?
2. What do you think about those justifications?
3. What is your reaction to Southam’s comment (pg 134) on why he did not inject himself?
Chapter 18: Strangest Hybrid (1960-1966)
1. Why were scientists worried that cell and tissue research was becoming a disaster?
2. Why did the Cell Culture Committee want to create a reference collection of cells?
3. Why was it so important that these cells came directly from the original source?
4. What are your thoughts about the fusion of animal and human cells?

Chapter 19: The Most Critical Time on This Earth is Now (1966-1973)
1. What was Joe trying to say when he wrote "the most critical time is now"?

Chapter 20: The HeLa Bomb?
1. What was the theory of spontaneous transformation? What significance did Gartler’s findings have for this theory?
2. Why was this report referred to as the “HeLa Bomb”?
3. Why will the effort to develop markers for HeLa contamination require contacting the Lacks family?

1. What was the original intent of Johns Hopkins in setting up the hospital? Did the doctors working at the hospital live up to that intent?
2. What were the night doctors and what impact did their activities have on American society?
3. Why do you think the Lacks family were not notified of what was being done with HeLa cells?

Chapter 22: The Fame She So Richly Deserves (1970-1973)
1. Would you volunteer to serve as a subject in medical research, as George Gey did? Explain.
2. What is the difference between epidermoid carcinoma and adenocarcinoma?
3. Would a correct diagnosis have changed the way Henrietta Lacks was treated?
4. Why was HeLa contamination a problem for research seeking a cancer virus?

Chapter 23: It’s Alive (1973-1974)
1. Do you think the investigators treated the Lacks family ethically? Explain.
2. How are ethical standards for research on humans today treated differently than they were in the 1970s?

Chapter 24: Least They Can Do (1975)
1. What are the interests and conflicts that you see between the Lacks family, Johns Hopkins, the biotech firms selling HeLa, and the general scientific community?

1. What is your position on the issue of ownership of tissues used in medical research? How does it compare to the authors position?

Chapter 26: Breach of Privacy (1981-1985)
1. Do you think that federal rules regarding patient confidentiality are necessary and why?
2. Do you think Michael Gold should have published the information on Henrietta Lacks without receiving permission from the family? Did he make enough of an effort to contact them?

1. What role do telomeres play in determining how many times a cell can divide?
2. What is the Hayflick Limit?
3. Should research manipulating DNA be allowed? Why or why not?

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1. Were the consequences of increased recognition of Henrietta Lacks positive or negative for the Lacks family? Explain.
2. Why did Johns Hopkins respond to Barbara Wyche’s letter as it did?

1. What does Deborah mean when she says (pg 235), “I do want to go see them cells, but I’m not ready yet”?
2. When Rebecca Skloot reaches for the medical records, Deborah snapped (pg 239); “We ain’t ready for that!” What does that response signify to you?

Chapter 30: Zakariyya (2000)
1. Zakariyya commented, “Only people that can get any good from my mother cells is the people that got money, and whoever selling them cells – they get rich off our mother and we got nothing”. What are your thoughts about this statement?

Chapter 31: HeLa, Goddess of Death (2000-2001)
1. How would you feel if you discovered that your mother’s cells had been used in so many different research programs? How does your reaction compare to Deborah’s reaction?

Chapter 32: All That’s My Mother (2001)
1. Zakariyya acted very different when he left the lab. Why do you think that was?

Chapter 33: The Hospital for the Negro Insane (2001)
1. What was your reaction to the description of the conditions and studies being done at Crownsville back in the 1950s?

Chapter 34: The Medical Records (2001)
1. What are your thoughts about the events that occurred in this chapter?

Chapter 35: Soul Cleansing (2001)
1. What are your thoughts about the events that occurred in this chapter?

Chapter 36: Heavenly Bodies (2001)
1. Which explanation for the immortality of Henrietta’s cells seems better, or more correct, to you? Why?

Chapter 37: Nothing to be Scared About (2001)
1. Why is this chapter named “Nothing to be Scared About”?

Chapter 38: The Long Road to Clover (2009)
1. What are your thoughts about the events that occurred in this chapter?

Afterword
1. What is the Common Rule regarding individual rights in research?
2. Do you agree with the assertion that people are morally obligated to allow tissues taken during medical and diagnostic procedures to be used for research that could potentially help others? What restrictions, if any, should people be allowed to place on research using their tissues?
3. Should individuals have the right to claim control over products developed from their own tissues or cells? Explain.

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