

## The Immortal Life of Henrietta Lacks by Rebecca Skloot

“Her name was Henrietta Lacks, but scientists know her as HeLa. She was a poor black tobacco farmer whose cells—taken without her knowledge in 1951—became one of the most important tools in medicine, vital for developing the polio vaccine, cloning, gene mapping and more. Henrietta’s cells have been bought and sold by the billions, yet she remains virtually unknown, and her family can’t afford health insurance. This phenomenal *New York Times* bestseller tells a riveting story of the collision between ethics, race, and medicine; of scientific discovery and faith healing; and of a daughter consumed with questions about the mother she never knew.”

-Rebecca Skloot-Summary taken from the book jacket

We will be reading this fascinating story about Henrietta, her cells and her family. You will be asked to respond to questions and listen to the author about the writing process. ~~The answers to the questions must be typed and turned in according to the due date calendar provided.~~

**Before we beginning reading please go to our class website and look for Rebecca Skloot’s website press page.**

<http://rebeccaskloot.com/the-immortal-life/press/>

You will see 3 videos and several radio interviews with the author Rebecca Skloot.

Watch **one** video- besides the Colbert video- and listen to **one** radio interview. For the two video links that don’t work, working links are on our class page. Answer the following questions

1. What do you think this book is going to be about?
2. Was there anything that jumped out at you from the interviews—anything interesting or intriguing?

### **Prologue**

1. The author uses several similes to describe cells. What similes does she use to describe the way a cell looks? What simile does she use to explain the functions of the different parts of a cell? What do these similes suggest about biology?
2. What is mitosis? What beneficial biological processes involve mitosis?
3. What simile does Donald DeFler use to describe mitosis?
4. What happens when there is a mistake during the process of mitosis?
5. According to DeFler, how important was the discovery of HeLa cells?
6. As a high school student, Skloot began researching HeLa cells to find out more about Henrietta Lacks. Examine page 5 and 6 and write down each step that Skloot took to begin her research?
7. Why are Henrietta cells considered immortal?
8. What research were Henrietta’s cells a part of?

### **Chapter 1: The Exam**

1. Why does Sadie think Henrietta hesitated before seeing a doctor?
2. What did Henrietta’s first doctor assume the source of the lump on Henrietta’s cervix was? What stereotype of bias might this assumption be based on?
3. Why did David Lacks take Henrietta to the public wards at John Hopkins instead of a closer hospital?
4. After Henrietta is examined by Dr. Jones, the doctor noted that she recently had a baby—six weeks ago—the doctor at the time didn’t find the cancer. Why did this concern Dr. Jones?

## **Chapter 2: Clover**

1. Why did Henrietta end up being raised by her grandfather, Tommy Lacks?
2. What are the connotations of the term “home-house”? What does this term suggest about the values of the Lacks family?
3. Skloot uses vivid imagery and details to describe Henrietta’s childhood in Clover. Locate a passage that you found particularly effective or memorable, and explain why you selected it?
4. Compare the medical terms describing Elsie’s condition with the terms used by Henrietta’s friends and family. What are the connotations of the two sets of terms?
5. How did Pearl Harbor change life in Turner Station?
6. Contrast the working conditions of black workers and white workers at the Sparrows Point Steel Mill.

## **Chapter 3: Diagnosis and Treatment**

1. What are the two different types of cervical cancer?
2. Doctors at the time often misdiagnosed cervical cancer. Why?
3. Explain how the development of the Pap smear improved the survival rate of women diagnosed with cervical cancer?
4. How did doctors justify using patients in public hospital wards as medical research subjects without obtaining their consent or offering them financial compensation? Do you agree or disagree with their reasoning? Explain your answer
5. What was George Gey’s position at Johns Hopkins
6. How was cervical cancer created at the time?
7. Henrietta signed a consent form that said, “I hereby give consent to the staff of the Johns Hopkins Hospital to perform any operative procedures and under any anesthetic either local or general that they may deem necessary in the proper surgical care and treatment of : \_\_\_\_\_” (page 31). Based on this statement, do you believe Telinde and Gey had the right to obtain a sample from her cervix to use in their research? What information would they have had to give her for Henrietta to give informed consent? Do you think Henrietta would have given explicit consent to have a tissue sample used in medical research if she had been given all the information? Do you always thoroughly read consent forms before signing them?

## **Chapter 4: The Birth of HeLa**

1. Why was it difficult to grow cells in a lab? Whose lab were the cells grown in?
2. Where did the name “HeLa” come from?
3. Explain how Gey’s roller-tube culturing technique works?
4. What happened to the HeLa cells that Mary cultured?
5. Gey chose to give away samples of HeLa to his colleagues almost immediately. Do you think this was a good decision? Explain your answer
6. Once HeLa started growing, was Henrietta informed that her cells were being used in Gey’s research?

## **Chapter 5: “Blackness Be Spreadin All Inside”**

1. What was Elsie’s early life like?
2. Why did Henrietta and David (Day) Lacks decide to place Elsie in the Hospital for the Negro Insane?
3. What important information did Henrietta’s doctor fail to give her before starting her cancer treatment? How did she react when this information was eventually shared with her?

## **Chapter 6: “Lady’s on the Phone”**

1. Explain who Roland Pattillo is. How is he connected to both Henrietta Lacks and George Gey?
2. Why do you think Pattillo agreed to help Skloot contact Henrietta’s family?
3. How does Deborah Lacks initially respond to Skloot’s request for information?
4. What questions does Deborah have about her mother?
5. How does Day initially respond to Skloot’s request for information?

## **Chapter 7: The Death and Life of Cell Culture**

1. What did Gey hope to accomplish with HeLa cells?
2. What did HeLa allow scientists to do for the first time?
3. Who was Alexis Carrel? Why did he win the Nobel Prize?
4. How did the media react to Carrel’s announcement that he had grown immortal chicken heart cells?
5. What controversial beliefs did Carrell have?
6. Give an example of propaganda that was used to fuel the public’s fear and distrust of tissue culture
7. What details suggest that Carrel’s claims about the immortal cell line were not scientifically sound?
8. Why didn’t the public pay attention to when Henrietta’s cells were finally grown in the lab?

## **Chapter 8: “A Miserable Specimen”**

1. After her initial round of treatment, what did Henrietta’s doctors assume about the effectiveness of the radium therapy?
2. When did the doctors realize that Henrietta had been correct about the growth of her cancer?
3. What does the use of the term “a miserable specimen” by Henrietta’s doctors reveal about their attitude toward her?

## **Chapter 9: “Turner Station”**

1. How does Skloot proceed with her research when it becomes clear that Sonny Lacks is not going to meet with her?
2. Compare and contrast the Turner Station that Skloot visited in 1999 with the Turner Station that Henrietta experienced as a young woman?
3. What does Skloot realize after watching the BBC documentary about HeLa?

## **Chapter 10: The Other Side of the Tracks**

1. What do the names of the creek and the river suggest about life in Lacks Town?
2. How was Cootie related to Henrietta?
3. Cootie seems to know and understand a little bit about HeLa cells, but he believes that Henrietta’s spirit is still present in her cells. What does Cootie think about the reason that HeLa cells were used to develop a polio vaccine?
4. Where does Cootie think Henrietta’s cancer came from?

## **Chapter 11: “The Devil of Pain Itself”**

1. Describe the progression of Henrietta’s cancer in the eight months between her diagnosis and her death
2. Why did doctors stop giving Henrietta blood transfusion?
3. What was Henrietta’s final request? What does this request tell you about her?

## **Chapter 12: The Storm**

1. Why did Henrietta's doctors need to ask for her family's permission to remove tissue samples after her death? How did Day initially respond to their request?
2. What did Mary, Gey's assistant realize when she saw Henrietta's painted toenails? How was the timing of this realization ironic?

## **Chapter 13: The HeLa Factory**

1. What was the purpose of the HeLa factory?
2. What unusual characteristics of HeLa cells made them ideal for use in the polio vaccine trials?
3. Explain the inherent irony of the fact that the Tuskegee HeLa production lab was operating at the same time that the infamous syphilis study was being conducted. What does the juxtaposition of these two projects reveal about race relations in the early 1950's?
4. Paraphrase the explanation of how a virus reproduces found on page 97. Why did the fact that HeLa cells are malignant make them particularly useful in the study of viruses?
5. Why was the development of methods of freezing cells an important scientific breakthrough?
6. Why is standardization important in scientific research?
7. Why did scientists want to be able to clone cells for research?
8. Explain the contribution that HeLa made to the emerging field of genetics?
9. Even though the HeLa cells were cancerous they could still experiment with them, why?
10. In a few short years after Henrietta's death science made a few large discoveries. Name at least 2.

## **Chapter 14: Helen Lane**

1. How soon after Henrietta's death did the media attempt to write about her?
2. What reasons did Berg give for wanting information about the woman whose cells were used to grow HeLa?
3. A reporter named Roland Berg wanted to do a story about Henrietta. Why did Gey and the other doctors not want to release her name to the reporter?
4. Summarize the various factual errors that appeared in the stories about HeLa

## **Chapter 15: "Too Young to Remember"**

1. How old were Henrietta's oldest and youngest children when their mother died?
2. What questions did Deborah have about her mother and sister?

## **Chapter 16: "Spending Eternity in the Same Place"**

1. How are the white and black Lackses related? Who are their common ancestors?
2. How did Henrietta's family acquire the land that became known as Lacks Town?  
From Albert Lacks which was Henrietta's maternal great-grandfather
3. Compare and contrast the different attitudes the white and black Lacks family members held about race

## **Chapter 17: Illegal, Immoral, Deplorable**

1. What was Chester Southam concerned that HeLa cells might do?
2. Describe the experiment that Southam developed to test his hypothesis about HeLa.
3. Who were the test subjects in Southam's first study? Were they informed about the research and its risks?
4. What was the result of Southam's first research study? Based on these results, did his hypothesis appear to be correct?
5. Where did Southam find test subjects for his second research study?

6. Based on the results of the second study, what two things did Southam believe that injections of HeLa cells might be able to do?
7. How did Southam justify his decision to inject HeLa cells into patients without their knowledge or consent?
8. What does the term “informed consent” mean?
9. Explain how the action against Southam and Mandel led to the development of informed consent forms as a standard medical practice.

### **Chapter 18: “Strangest Hybrid”**

1. Summarize the various ways that HeLa was used in the space program.
2. What disturbing discovery did scientists make about the way HeLa responded in orbit?
3. Why did a committee of scientists form the American Type Culture Collection (ATCC)?
4. Why did scientists want to fuse human and animal cells?
5. What scientific discoveries were made possible as a result of fused hybrid cells?
6. How did the public respond to the idea of cell hybrids? In what specific ways did the media influence the public’s perception of cell hybrids?
7. What type of findings did researchers discover by combining HeLa cells with mouse and chicken cells?

### **Chapter 19: “The Most Critical Time on This Earth is Now”**

1. Analyze the note that Joe wrote to the judge. What does it tell you about Joe’s personality and background?
2. What was the lawyer’s main argument in Joe’s defense?
3. How did prison change Joe?

### **Chapter 20: The HeLa Bomb**

1. Explain the meaning of the idiomatic expression “to drop a bomb.”
2. What did Stanley Gartler discover about eighteen of the most commonly used cell cultures?
3. How was Gartler able to link the contamination problem to HeLa?
4. What unique abilities did HeLa have that allowed it to contaminate cultures without researchers being aware that contamination had occurred?
5. Why would HeLa contamination be a problem for researchers?
6. What is “spontaneous transformation”? What did Gartler suggest about spontaneous transformation?
7. How did the scientific community respond to Gartler’s theory about HeLa contamination?
8. Why did scientists need to test if HeLa cells were present in culture?

### **Chapter Twenty-One: Night Doctors**

1. Explain the connection that Sonny makes between his mother’s personality and the ways he believes HeLa cells have been used.
2. What do the Lackses believe Johns Hopkins did to black people?
3. What are “night doctors”? Where did the term originate and why? What do the Lackses believe “night doctors” do? Is their belief based on real events? Explain your answer.
4. Why did Johns Hopkins start a medical school and hospital in a poor black neighborhood? What purpose was the school/hospital intended to serve?
5. What does the 1969 Johns Hopkins study reveal about the researcher’s attitude and assumptions about race?
6. Why is the fact that the Lacks family cannot get health insurance an example of irony?

7. What is the Lacks family's biggest complaint about the way they have been treated by Johns Hopkins and Dr. Gey?

### **Chapter 22: "The Fame She So Richly Deserves"**

1. What type of cancer was George Gey diagnosed with?
2. What specific request did Gey make prior to going into surgery? Why didn't his surgeons honor his request?
3. Do Gey's attitude and actions after his own diagnosis of terminal cancer change your opinion of him? Explain your answer.
4. What did Howard Jones realize when he reviewed Henrietta's medical records?
5. What was the purpose of President Nixon's National Cancer Act?
6. Explain how Henrietta's real name became public knowledge.
7. Do you agree that Henrietta should have been correctly identified in order to "give her the fame she so richly deserves," or do you think her anonymity should have been protected? Explain your answer.
8. It was found out in 1971 that Henrietta's cancer was misdiagnosed. What implications did this have?

### **Chapter 23: It's Alive**

1. How long had Henrietta been dead when her family found out that her cells were still alive?
2. Why did researchers want DNA samples from Henrietta's family?
3. Did researchers explain why they wanted DNA samples to the Lacks family? Did the family give informed consent for the research done on those samples?
4. From a legal standpoint, how is the fact that the doctors failed to obtain consent prior to taking blood from the Lacks family in 1973 different from their initial failure to obtain consent from Henrietta in 1951?
5. What were some of Deborah's fears and concerns after she found out that her mother's cells were still alive?

### **Chapter 24: "Least They Can Do"**

1. How did Rogers discover Henrietta's real name?
2. Describe Rogers's interaction with the Lacks family.
3. Paraphrase the paragraph in Rogers's article that the Lacks family found extremely upsetting. What conclusion did they draw about George Gey and Johns Hopkins?
4. What facts about George Gey's life support the assertion that he never personally profited from the development of HeLa?
5. Explain how the sale of HeLa evolved into a business. Describe the extent to which the profits from that business are likely a direct result of the sale of HeLa cells. In what other ways do scientists, corporations, and individuals profit as a result of HeLa?
6. Why did Deborah begin researching her mother's cells? What effect did her research have on her?
7. What information about the Lackses was published by McKusick and Hsu? Why is the publication of this information troubling from an ethical and legal standpoint?
8. Why do you think Skloot ends this chapter with the introduction of John Moore's story?

## **Chapter 25: “Who Told You You Could Sell My Spleen?”**

1. Summarize John Moore’s story.
2. Describe the lawsuit that set a legal precedent for patenting biological “products” such as cell lines.
3. Why did Ted Slavin start Essential Biologicals?
4. Why did scientists find the Moore lawsuit deeply troubling?
5. Summarize the pros and cons of giving patients legal ownership of their cells.
6. What was the Supreme Court of California’s decision regarding the Moore lawsuit?
7. Do you agree with the court’s ruling? Explain your answer.
8. Why did Moore sue Golde in 1984?

## **Chapter 26: Breach of Privacy**

1. Why did Deborah choose not to request a copy of her mother’s medical records?
2. In spite of her deliberate decision to not read her mother’s medical records, Deborah Lacks still learned extremely upsetting details about her mother’s illness and autopsy. Describe how Deborah found out about her mother’s painful death.
3. Explain why Gold’s journalism could be considered irresponsible and/or unethical.

## **Chapter 27: The Secret to Immortality**

1. Explain how the human papillomavirus (HPV) causes cervical cancer.
2. Are scientists able to definitively explain why HeLa grew so powerfully?
3. Explain the theories that Henrietta’s family have about why her cells are so powerful.
4. Describe the contribution that HeLa has made to research on the HIV virus and the AIDS epidemic.
5. Explain Van Valen’s theory that HeLa cells are “no longer human.” Was his theory accepted by the scientific community?
6. According to Stevenson, why did scientists develop the argument that HeLa cells are no longer human?
7. How did Henrietta’s cancer start?
8. There is a string of DNA at the end of each chromosome called the telomere. What is its significance?

## **Chapter 28: After London**

1. What did Deborah hope would happen as a result of the BBC documentary?
2. What motivated Pattillo to organize the HeLa Cancer Control Symposium?  
He worked in Gey’s lab and felt connected to her and he wanted to honor her contributions to science page 219
3. Describe the attempts Wyche made to get recognition for Henrietta and her family.
4. Describe Keenan Kester Cofield. Why did he get involved with the Lacks family?
5. How did Deborah discover the truth about Cofield?
6. What did Cofield do when he realized that the Lacks family had blocked his access to their family records? What were the results of his actions?
7. Explain Deborah’s fears regarding her sister, Elsie.

## **Chapter 29: A Village of Henriettas**

1. What specific things did Deborah ask Skloot to promise she would do?
2. Explain the significance of the gift that Skloot delivered to Deborah at their first meeting.
4. What information about her mother was Deborah unwilling to share with Skloot? Why do you think she was so protective of this information?
5. Dr. Christoph Lengauer developed a technique to take pictures of chromosomes. What did Lengauer send Deborah?

### **Chapter 30: Zakariyya**

1. Why wasn't Skloot excited about meeting Zakariyya?
2. Look back over Skloot's description of Zakariyya's apartment. What do the contents of the apartment tell you about his life and personality? What is important to him?
3. Zakariyya uses the term "disrespect" to describe Gey's treatment of Henrietta and the family. Explain the specific reasons why Zakariyya feels disrespected. Do you believe Gey was disrespectful? Explain your answer.
4. What gift does Deborah give Zakariyya? Do you think Zakariyya should be the one to have this object? What does this gift tell you about Deborah's feelings about her family?

### **Chapter 31: Hela, Goddess of Death**

1. What does Deborah say about people who frame her mother's story as a story about racism?
2. How did Skloot finance the research for her book? What did she promise to do for the
3. Why did Deborah decide to go see her mother's cells? What obstacle almost kept her from doing so?

### **Chapter 32: "All That's My Mother"**

1. Compare and contrast Skloot's, Deborah's, and Zakariyya's interactions with the Jesus statue at Johns Hopkins. What do these interactions reveal about their attitudes toward religious faith?
2. Analyze the way that Christoph Lengauer interacts with the Lacks family. Why do you think his interaction is so different from anyone the Lackses encountered at Johns Hopkins up until this point?
3. What belief of Deborah's does Lengauer's attitude affirm?
4. What important misunderstanding about HeLa does Lengauer clarify for Deborah?
5. Why did Christoph lab need a ventilation system and why did they keep HeLa cells separate from other cells?

### **Chapter 33: The Hospital for the Negro Insane**

1. Does the title of this chapter evoke an emotional response from you? Why do you think Skloot chose this title?
2. Why did Deborah and Skloot travel to Crownsville?
3. Who is Paul Lurz? Which comments of his foreshadow that something terrible happened to Elsie?
4. Why were the hospital's medical records from the 1950s and earlier disposed of?
5. What part of Elsie's medical records did Lurz have? Why had he saved patients' medical records? Why was he surprised that he had Elsie's records in particular?
6. Skloot carefully describes the photograph of Elsie. What specific things can you infer about Elsie's treatment based on the description of the photograph?
7. Consider Deborah's comment on page 276: "Like I'm always telling my brothers, if you gonna go into history, you can't do it with a hate attitude. You got to remember, times was different." Is it possible to approach history from an objective point of view? If so, how and why is this important, especially in the context of Henrietta's story?

### **Chapter 34: The Medical Records**

1. What causes the confrontation between Deborah and Skloot? How is it resolved?
2. What reason does Deborah give for not wanting Skloot to type out Henrietta's records word-for-word?
3. Why do you think Deborah breaks out in hives after visiting Crownsville and giving Skloot access to the medical records?



### **Chapter 35: Soul Cleansing**

1. How are Gladys and Gary related to Deborah?
2. Gary tells Deborah that her quest to find out about Elsie and Henrietta has been a way of “honoring her mother.” Explain what he means by saying this.
3. After witnessing the amount of physical and emotional anguish that Deborah is in, Gary begins to preach and lay hands on Deborah. What burden does he ask to be lifted from Deborah? Where does he ask the burden to be placed?
4. How does Deborah respond after Gary’s prayer?

### **Chapter 36: Heavenly Bodies**

1. Summarize Gary’s spiritual explanation for why Henrietta’s cells lived on after her death.
2. Discuss the impact that witnessing the interaction between Gary and Deborah—and, later, talking with Gary—had on Skloot. What new perspective did she gain after these experiences?

### **Chapter 37: “Nothing to Be Scared About”**

1. What physical ailments did Deborah suffer from as a result of the excitement and stress of seeing her mother’s cells for the first time, and learning about Elsie?
2. Why did Deborah decide to go back to school?
3. Why was Deborah unable to attend the National Foundation for Cancer Research’s Henrietta Lacks conference? September 11<sup>th</sup>
4. Explain how Davon’s heroic actions saved Deborah’s life.

### **Chapter 38: The Long Road to Clover**

1. What string of events in 2009 suggests that, if Skloot had not begun researching Henrietta’s story a decade earlier, it may have been lost forever?
2. At the time of this book’s publication, how had the lives of Henrietta’s great- and greatgreat-grandchildren been affected by Skloot’s research, and by the knowledge and understanding of Henrietta’s contribution to science?
3. Skloot begins and ends the book with Deborah’s voice. How does this choice impact the reader’s experience of the story?

### **Where They Are Now/Afterword**

1. How did Deborah’s death change the lives of her brothers?
2. What legal options do the Lackses have? What is their position on suing over the use of HeLa?
3. If Henrietta Lacks could know how important her cells have been to science, do you think she would approve of the fact that they were taken from her without her knowledge or consent? Explain your answer.
4. Some of the questions that Rebecca gets from people are “Wasn’t it illegal for doctors to take Henrietta’s cells without her knowledge? Don’t doctors have to tell you when they use your cells for research?” What are the answers to these questions?
5. In 1999 there were 307 million tissue samples stored in the U.S. alone. What are researchers doing with these samples?
6. Deborah says, “But I always have thought it was strange, if our mother cells done so much for medicine, how come her family can’t afford to see no doctors? Don’t make any sense” (page 9). Should the family be financially compensated for the HeLa cells? If so, who do you believe that money should come from? Do you feel the Lackses deserve health insurance envy though they can’t afford it? How would you respond if you were in their situation?

7. The afterword discusses the patient's role in tissue research? Do you feel that people should have a right to decide if their "unwanted" tissue samples should be used for science?

8. As much of this book is about Henrietta Lacks, it is also about Deborah learning of the mother she barely knew, while also finding out the truth about her sister, Elsie. Imagine discovering similar information about one of your family members. How would you react? What questions would you ask?

9. This is a story with many layers. Though it's not told chronologically, it is divided into three sections. Discuss the significance of the titles given to each part: Life, Death, Immortality. How would the story have been different if it were told chronologically?