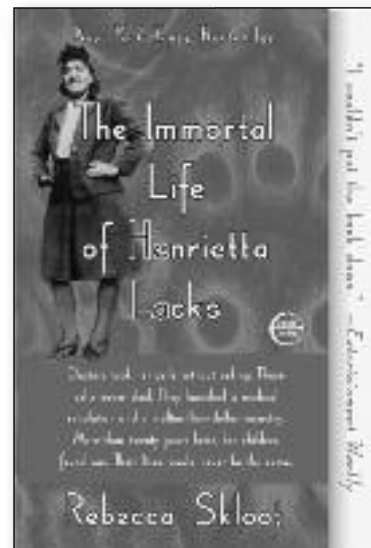




The Immortal Life of Henrietta Lacks

By *Rebecca Skloot*



This book is a popular common reading selection at high schools, colleges/universities, and “One City, One Book” Programs.

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“Using [*The Immortal Life of Henrietta Lacks*] in the classroom will deepen your students’ understanding of nonfiction, science, medicine, and history—but more than that, it will prepare them to engage thoughtfully with the profound moral and ethical dilemmas posed by emergent technologies and the world we share.”

—Amy Jurskis, Tri-Cities High School, East Point, Georgia

“Skloot narrates the science lucidly, tracks the racial politics of medicine thoughtfully, and tells the Lacks family’s often painful story with grace . . . Science writing is often just about the ‘facts.’ Skloot’s book, her first, is far deeper, braver, and more wonderful. . . . Made my hair stand on end.”

—*The New York Times Book Review*

“Heartbreaking and powerful, unsettling yet compelling, *The Immortal Life of Henrietta Lacks* is a richly textured story of the hidden costs of scientific progress. Deftly weaving together history, journalism and biography, Rebecca Skloot’s sensitive account tells of the enduring, deeply personal sacrifice of this African American woman and her family and, at long last, restores a human face to the cell line that propelled 20th century biomedicine. A stunning illustration of how race, gender and disease intersect to produce a unique form of social vulnerability, this is a poignant, necessary and brilliant book.”

—Alondra Nelson, Associate Professor of Sociology, Columbia University; editor of *Technicolor: Race, Technology and Everyday Life*

“*The Immortal Life of Henrietta Lacks* is an ideal book for classroom discussions in bioethics, history of science, and journalism. Author Rebecca Skloot does an exceptional job of raising critical issues that should encourage both scholars and students to reevaluate the research decision making process, the way research subjects are treated, and the balance of power in this country as determined by race, economics, and even education. An incredibly readable and smart text that should be a part of countless university discussions.”

—Deborah Blum, Helen Firstbrook Franklin Professor of Journalism, University of Wisconsin-Madison; author of *The Poisoner’s Handbook: Murder and The Birth of Forensic Medicine in Jazz Age New York*

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• about the book

In 1950, Henrietta Lacks, a young mother of five children, entered the colored ward of The Johns Hopkins Hospital to begin treatment for an extremely aggressive strain of cervical cancer. As she lay on the operating table, a sample of her cancerous cervical tissue was taken without her knowledge or consent and given to Dr. George Gey, the head of tissue research. Gey was conducting experiments in an attempt to create an immortal line of human cells that could be used in medical research. Those cells, he hoped, would allow scientists to unlock the mysteries of cancer, and eventually lead to a cure for the disease. Until this point, all of Gey's attempts to grow a human cell line had ended in failure, but Henrietta's cells were different: they never died.

Less than a year after her initial diagnosis, Henrietta succumbed to the ravages of cancer and was buried in an unmarked grave on her family's land. She was just thirty-one years old. Her family had no idea that part of her was still alive, growing vigorously in laboratories—first at Johns Hopkins, and eventually all over the world.

Thirty-seven years after Henrietta's death, sixteen-year-old Rebecca Skloot was a high school student sitting in a biology class when her instructor mentioned that HeLa, the first immortal human cell line ever grown in culture, had been taken from an African American woman named Henrietta Lacks. His casual remark sparked Skloot's interest, and led to a research project that would take over a decade to complete. Her investigation of the true story behind HeLa eventually led her to form significant—and in some cases, life-changing—relationships with the surviving members of the Lacks family, especially Henrietta's daughter, Deborah.

In telling Henrietta's story, Skloot draws from primary sources and personal interviews to provide insightful narrative accounts of Henrietta's childhood, young adulthood, diagnosis, illness, and tragic death. She also explores the birth and life of the immortal cell line HeLa, and shows how research involving HeLa has changed the landscape of medical research, leading to not only scientific and medical breakthroughs, but also new and evolving policies concerning the rights of patients and research subjects.

As the story of HeLa unfolds, so does the story of Henrietta's surviving children, who for two decades were unaware of the existence of their mother's cells—and the multimillion-dollar industry that developed around the production and use of HeLa. Central to this narrative is the relationship between Skloot and Deborah. As Skloot tenaciously worked to gain Deborah's trust, Deborah struggled to understand what had happened to her mother and her mother's cells. The result of their relationship is an illuminating portrait of the enduring legacy of Henrietta's life, death, and immortality.



• about the author

REBECCA SKLOOT is an award-winning science writer whose articles have appeared in *The New York Times Magazine*; *O*, *The Oprah Magazine*; *Discover*; *Prevention*; *Glamour*; and others. She has worked as a correspondent for NPR's *Radiolab* and PBS's *NOVA scienceNOW*, and is a contributing editor at *Popular Science* magazine and guest editor of *The Best American Science Writing 2011*. Her work has been anthologized in several collections, including *The Best Creative Nonfiction*. She is a former vice president of the National Book Critics Circle, and has taught creative nonfiction and science journalism at the University of Memphis, the University of Pittsburgh, and New York University. She lives in Chicago. *The Immortal Life of Henrietta Lacks* is her first book. It is being translated into more than twenty languages and adapted into an HBO film produced by Oprah Winfrey and Alan Ball. She is the Founder and President of the Henrietta Lacks Foundation. For more information, visit her website at RebeccaSkloot.com, where you'll find links to follow her on Twitter and Facebook.

• about the guide

The Immortal Life of Henrietta Lacks contains three main narratives, each with unique applications to the disciplines of language arts, history, and science. As a result, this guide is structured to provide discussion and writing activities that will engage students in researching, reading, and writing across the curriculum.

Guided Reading and Discussion Questions are provided for each chapter. These questions encourage students to engage in a close reading of the text, prompting them to clarify or infer meaning and to pause to examine not only *what* is written, but *how* it is written. *Writing Prompts* are thematic and organized in sections that may be of special interest to the disciplines of language arts, social studies, and science. These prompts guide students toward an in-depth analysis of the themes and issues central to the story of Henrietta Lacks, and several may promote outside reading or research. Teachers are encouraged to adapt some of the prompts for use in debates or Socratic seminars. The questions in the final section, *Topics for Further Discussion*, require students to expand their thinking and engage in significant research activities related to subjects or issues raised in the book. Many of these topics could be easily applied to group projects.

There are many excellent multimedia resources related to this book available on the author's website at RebeccaSkloot.com. Links to several radio productions and podcasts are provided at the end of the guide. Teachers are strongly encouraged to share the *Radiolab* episode with their students, as it includes audio recordings that the author taped while researching the book, and illuminates several key scenes from the book.

• before you read

Point out the differences between the genres of historical fiction and nonfiction. Define “creative nonfiction,” a genre in which all facts are accurate and verifiable, but presented in a creative way that emphasizes storytelling through the use of scenes, dialogue, and other techniques more often found in fiction. Discuss the differences between creative nonfiction and traditional journalism. Discuss the methods by which a nonfiction writer is able to recreate dialogue and recount descriptions of historical events and locations. Direct students to carefully examine the endnotes and foreword of the book, and discuss the specific steps and sources that the author used to ensure that the narrative account of Henrietta's life is factual and accurate.

As a writing assignment, have students practice writing completely factual and objective narrative descriptions of historical locations or figures based on primary source documents such as photographs, eyewitness accounts, testimonies, and public records.

• guided reading and discussion questions

Prologue: The Woman in the Photograph

1. The author uses several similes to describe cells. What simile 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 pages 5 and 6 and write down each step that Skloot took to begin her research.

Chapter One: The Exam

1. How long did Henrietta wait between first telling her girlfriends that “something didn’t feel right” and going to the doctor?
2. Why does Sadie think Henrietta hesitated before seeing a doctor?
3. What did Henrietta’s first doctor assume the source of the lump on Henrietta’s cervix was? What stereotype or bias might this assumption be based upon?
4. Why did David Lacks take Henrietta to the public wards at Johns Hopkins instead of a closer hospital?
5. Explain what the Jim Crow laws were.
6. Who was Henrietta’s gynecologist?
7. Review the notes on Henrietta’s medical history found on page 16. Based on the objective details in her medical chart, what can you infer about Henrietta’s life and personality?
8. Based on her medical chart, how would you describe Henrietta’s feelings about doctors?
9. What did Howard Jones find “interesting” about Henrietta’s medical history? What does this finding suggest about Henrietta’s cancer?

Chapter Two: 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. How was Day related to Henrietta?
4. 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.
5. Describe the relationship between Crazy Joe and Henrietta.
6. How old was Henrietta when she had her first child with Day?
7. What was different about Henrietta’s second child, Elsie?

• guided reading and discussion questions (continued)

8. 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?
9. How did Pearl Harbor change life in Turner Station?
10. Contrast the working conditions of black workers and white workers at the Sparrows Point Steel Mill.

Chapter Three: Diagnosis and Treatment

1. How are different types of cancer categorized?
2. Summarize Dr. TeLinde's position in the debate over the treatment of cervical cancer.
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. How did TeLinde hope to prove that his hypothesis about cervical cancer was correct?
6. What was George Gey's position at Johns Hopkins?
7. Explain what an immortal cell line is.
8. Explain how TeLinde and Gey's relationship led to Gey obtaining a tissue sample from Henrietta's tumor.
9. Analyze the consent statement that Henrietta signed on 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?
10. Do you think Henrietta would have given explicit consent to have a tissue sample used in medical research if she had been asked? Do you think she would have understood what was being asked of her? Explain your answers.
11. Were cells taken only from black patients? Were black patients generally treated differently from white patients in the early 1950s? Explain your answers.

Chapter Four: The Birth of HeLa

1. Summarize the main obstacles Gey and his assistants faced in their effort to grow cells.
2. Where did the name "HeLa" come from?
3. Based on the descriptions of Gey found on pages 38–39, offer three adjectives that best describe his personality.
4. Explain how Gey's roller-tube culturing technique works.
5. What happened to the HeLa cells that Mary cultured?
6. Gey chose to give away samples of HeLa to his colleagues almost immediately. Do you think this was a good decision? Explain your answer.
7. Once HeLa started growing, was Henrietta informed that her cells were being used in Gey's research?
8. What is the implication of the author's decision to use the term "birth" to describe the initial growth of HeLa cells?

• guided reading and discussion questions (continued)

Chapter Five: “Blackness Be Spreadin All Inside”

1. After her diagnosis and treatment, how did Henrietta behave? What can you infer about her personality based on this behavior?
2. According to Ethel’s cousins, why did she dislike Henrietta?
3. What was Elsie’s early life like?
4. Why did Henrietta and David (Day) Lacks decide to place Elsie in the Hospital for the Negro Insane?
5. What specific details let the reader know that sending Elsie away was difficult for Henrietta?
6. Why do you think Henrietta initially chose not to tell people about her cancer diagnosis? What does this decision suggest about Henrietta’s personality?
7. 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 Six: “Lady’s On the Phone”

1. Explain who Roland Pattillo is. How is he connected to both Henrietta Lacks and George Gey?
2. Paraphrase the information on page 50 describing the Tuskegee Syphilis Study.
3. What do the Tuskegee Syphilis Study and the Mississippi Appendectomies suggest about the history of African Americans and medicine?
4. Why do you think Pattillo agreed to help Skloot contact Henrietta’s family?
5. What does Pattillo tell Skloot about Elsie Lacks?
6. How does Deborah Lacks initially respond to Skloot’s request for information?
7. What questions does Deborah have about her mother?
8. How does Day initially respond to Skloot’s request for information?

Chapter Seven: 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 Carrel 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?

• guided reading and discussion questions (continued)

Chapter Eight: “A Miserable Specimen”

1. After her initial round of treatment, what did Henrietta’s doctors assume about the effectiveness of the radium therapy?
2. How did her doctors react to Henrietta’s intuitive conviction that the cancer was spreading inside of her?
3. In your own words, explain the paradox “benevolent deception.”
4. When did the doctors realize that Henrietta had been correct about the growth of her cancer?
5. What objective details suggest that Henrietta was in extreme pain at this point in her illness?
6. What objective details suggest that Henrietta was a devoted and loving mother?
7. What does the use of the term “a miserable specimen” by Henrietta’s doctors reveal about their attitude toward her?
8. While most accounts suggest that Henrietta never met George Gey or knew about HeLa, Laure Aurelian says that Gey recounted meeting with Henrietta before her death. Do you find this story believable? Use specific facts about Henrietta, Gey, and/or medical practice in the 1950s to support your opinion.
9. If Gey did speak to Henrietta just before she died, do you think she would have understood what immortal cells were? Explain your answer.

Chapter Nine: 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 the fact that the town still has “more than ten churches” suggest about the people in Turner Station?
4. Who is Courtney “Mama” Speed, and how is she connected to Henrietta Lacks?
5. What subjective conclusions can you make about Mama Speed based on the objective details on page 72?
6. Make a prediction based on the foreshadowing regarding Mr. Cofield. What do you think Cofield did?
7. What does Skloot realize after watching the BBC documentary about HeLa?

Chapter Ten: The Other Side of the Tracks

1. Explain the meaning of the idiom “the other side of the tracks.”
2. What do the names of the creek and the river suggest about life in Lacks Town?
3. How was Cootie related to Henrietta?
4. What illness did Cootie have as a child?

• guided reading and discussion questions (continued)

5. 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?
6. Where does Cootie think Henrietta's cancer came from?

Chapter Eleven: "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 transfusions?
3. What did Henrietta's friends and family do when they found out that she needed blood? Why do you think they were willing to sacrifice to help her?
4. What was Henrietta's final request? What does this request tell you about her?

Chapter Twelve: 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 made Day change his mind and allow the autopsy?
3. What did Mary, Gey's assistant, realize when she saw Henrietta's painted toenails? How was the timing of this realization ironic?
4. What happened when the family started to bury Henrietta's body?
5. Henrietta's cousin says that Henrietta "was tryin' to tell us somethin' with that storm." What do you think she could have been trying to say?

Chapter Thirteen: The HeLa Factory

1. Explain how a neutralization test is used to determine a vaccine's efficacy.
2. What unusual characteristics of HeLa cells made them ideal for use in the polio vaccine trials?
3. Why did the Tuskegee Institute become involved in the mass production of HeLa cells? Describe the depth of the Institute's involvement.
4. 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 1950s?
5. 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?
6. Why was the development of methods of freezing cells an important scientific breakthrough?
7. Why is standardization important in scientific research?
8. Why did scientists want to be able to clone cells for research?
9. Explain the contribution that HeLa made to the emerging field of genetics.

• guided reading and discussion questions (continued)

10. Describe the role Microbiological Associates played in the development of the field of cell culture, and the industry of selling HeLa cells and other human biological materials.
11. Who profited monetarily from the sale of HeLa cells and other human biological materials?
12. Do you agree with Pomerant's suggestion that Gey should have "finished his own research" before releasing HeLa to the general public?
13. In what ways, if any, did Gey personally profit from the development of HeLa?

Chapter Fourteen: 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. How did TeLinde, Gey, and others at Johns Hopkins respond to Berg's request? Why did they respond this way?
4. Summarize the various factual errors that appeared in the stories about HeLa.
5. Why didn't Henrietta's family know that her cells were still alive?
6. In what specific ways do you think that learning of HeLa soon after Henrietta's death might have changed her family members' lives?

Chapter Fifteen: "Too Young to Remember"

1. How old were Henrietta's oldest (Lawrence) and youngest (Joe) children when their mother died?
2. What reason did Ethel and Galen give for moving in with Day after Henrietta's death?
3. What did some family members think was the real reason Ethel moved in?
4. Describe the abuse that Joe suffered under Ethel's care. How did this abuse affect him?
5. Describe Deborah's childhood. What challenges did she have to overcome?
6. What questions did Deborah have about her mother and sister? Why do you think no one told her very much about them?

Chapter Sixteen: "Spending Eternity in the Same Place"

1. Describe Skloot's visit to the Lacks family cemetery. What impact does her use of imagery have on you as a reader?
2. According to Henrietta's cousin Cliff, what is "beautiful" about the idea of "slave-owning white Lackses being buried under their black kin"?
3. How are the white and black Lackses related? Who are their common ancestors?
4. How did Henrietta's family acquire the land that became known as Lacks Town?
5. Compare and contrast the different attitudes the white and black Lacks family members held about race.

• guided reading and discussion questions (continued)

Chapter Seventeen: Illegal, Immoral, and 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. Why, specifically, did the Jewish doctors at the Jewish Chronic Disease Hospital object to Southam's cancer study?
10. What is the purpose of the Nuremberg Code? What events led to it being developed?
11. According to State Attorney General Louis Lefkowitz, what do people have an "inalienable" right to?
12. What was the result of the legal action taken against Southam and Mandel?
13. Explain how the action against Southam and Mandel led to the development of informed consent forms as a standard medical practice.

Chapter Eighteen: "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. Explain what happens during somatic cell fusion.
5. Why did scientists want to fuse human and animal cells?
6. What scientific discoveries were made possible as a result of fused hybrid cells?
7. 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?

Chapter Nineteen: "The Most Critical Time on This Earth is Now"

1. How did Bobette respond to Deborah's pregnancy?
2. How was Joe's life different from his brothers' lives? What do you think caused this difference?
3. What crime did Joe commit?
4. How did Day, Sonny, and Lawrence respond to Joe's crime? What did they want Joe to do?
5. Why do you think Joe turned himself in to the police?

• guided reading and discussion questions (continued)

6. Analyze the note that Joe wrote to the judge. What does it tell you about Joe's personality and background?
7. What was the lawyer's main argument in Joe's defense?
8. How did prison change Joe?
9. Describe Deborah and Cheetah's marriage.
10. Why didn't Deborah go through with her plan to kill Cheetah? What did she do instead?

Chapter Twenty: 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?

Chapter Twenty-One: Night Doctors

1. What does the author's choice of descriptive details reveal to the reader about her impression of Sonny Lacks?
2. Explain the connection that Sonny makes between his mother's personality and the ways he believes HeLa cells have been used.
3. Sonny and Lawrence repeat the refrain "That's a miracle," when discussing the scientific advances made possible by their mother's cells. What does this refrain suggest about their worldview and values?
4. The description "His light brown face had grown tough with age, cracked but soft, like a pair of well-worn work boots," conveys a strong impression of Day Lacks. What does it suggest about his life and personality?
5. Give an example of indirect characterization that reveals that the Lacks family distrusts doctors.
6. What do the Lackses believe Johns Hopkins did to black people?
7. 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.
8. Why did Johns Hopkins start a medical school and hospital in a poor black neighborhood? What purpose was the school/hospital intended to serve?
9. What does the 1969 Johns Hopkins study reveal about the researcher's attitude and assumptions about race?

• guided reading and discussion questions (continued)

10. Why is the fact that the Lacks family cannot get health insurance an example of irony?
11. What is the Lacks family's biggest complaint about the way they have been treated by Johns Hopkins and Dr. Gey?

Chapter Twenty-Two: “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. After finding out that his cancer was terminal, what reason did Gey give for his decision to offer himself as a research subject?
4. Did Gey benefit or profit in any way from his participation in the research studies?
5. Do Gey's attitude and actions after his own diagnosis of terminal cancer change your opinion of him? Explain your answer.
6. What did Howard Jones realize when he reviewed Henrietta's medical records?
7. What was the purpose of President Nixon's National Cancer Act?
8. Explain how Henrietta's real name became public knowledge.
9. 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.

Chapter Twenty-Three: “It's Alive”

1. The title of this chapter contains an allusion to the classic horror movie *Frankenstein*. What does this allusion suggest about the tension between scientific discovery, and public perception and fear of such discoveries?
2. How did Bobette find out about HeLa?
3. How long had Henrietta been dead when her family found out that her cells were still alive?
4. Why did researchers want DNA samples from Henrietta's family?
5. 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?
6. Why did the Lacks family think the doctors were taking their blood?
7. 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?
8. What were some of Deborah's fears and concerns after she found out that her mother's cells were still alive?
9. Why did advances in genetic research necessitate establishing the legal requirement that doctors or researchers obtain informed consent documentation prior to taking DNA samples from patients for research?
10. Analyze the last paragraphs of this chapter. What does Hsu's request reveal about her attitude towards the Lackses? What does Skloot reveal by ending the chapter with Hsu's request?

• guided reading and discussion questions (continued)

Chapter Twenty-Four: “Least They Can Do”

1. What motivated Michael Rogers to find the Lacks family?
2. How did Rogers discover Henrietta’s real name?
3. Describe Rogers’s interaction with the Lacks family.
4. 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?
5. What facts about George Gey’s life support the assertion that he never personally profited from the development of HeLa?
6. 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?
7. Why did Deborah begin researching her mother’s cells? What effect did her research have on her?
8. 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?
9. Why do you think Skloot ends this chapter with the introduction of John Moore’s story?

Chapter Twenty-Five: “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? Summarize the reasoning behind the decision.
7. Do you agree with the court’s ruling? Explain your answer.

Chapter Twenty-Six: Breach of Privacy

1. Describe the changes that had taken place in the lives of Henrietta’s children by 1980.
2. Why did Zakariyya decide to participate in research studies at Johns Hopkins? What is ironic about his participation in these studies?
3. Why did Deborah choose not to request a copy of her mother’s medical records?
4. 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.
5. How did Deborah react after reading about her mother’s death?
6. Explain why Gold’s journalism could be considered irresponsible and/or unethical.

• guided reading and discussion questions (continued)

7. What do Gold's comments about his decision to publish private information without consulting the Lacks family reveal about his attitude toward them?
8. How have laws regarding medical privacy changed since the early 1980s?

Chapter Twenty-Seven: 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. Who do you think makes the more persuasive argument, Van Valen or Stevenson?
8. Explain the Hayflick limit.
9. Why are HeLa cells able to live beyond the Hayflick limit?

Chapter Twenty-Eight: 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?
3. Carefully reread the speech Deborah gave at Morehouse College, paying particular attention to her repetition of the word "understanding." Why do you think understanding HeLa was so important to Deborah? What obstacles does she mention as impeding her understanding?
4. How did the people in Turner Station react to the presence of the BBC film crew and news of Henrietta's newfound "fame"?
5. What was ironic about the creation of Speed and Wyche's Henrietta Lacks Foundation?
6. Why did Deborah agree to help Speed and Wyche with their museum project?
7. Describe the attempts Wyche made to get recognition for Henrietta and her family.
8. Analyze Johns Hopkins's official response to Wyche's letter. Do you feel that it is an appropriate response? What rhetorical strategies are used to counter Wyche's appeal?
9. Describe Keenan Kester Cofield. Why did he get involved with the Lacks family?
10. How did Deborah discover the truth about Cofield?
11. 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?
12. Explain Deborah's fears regarding her sister, Elsie.
13. Summarize the events in Deborah's life leading up to her initial contact with Rebecca Skloot. How do these events help explain Deborah's initial reluctance to talk with Skloot?

• guided reading and discussion questions (continued)

14. At the end of this chapter, with Skloot's phone call, the three narrative threads in the book come together as one, and from this point on, the story moves forward chronologically, no longer moving back and forth between different time periods. Why do you think Skloot structured the book this way?

Chapter Twenty-Nine: A Village of Henriettas

1. Why do you think Deborah eventually decided to talk with Skloot?
2. What specific things did Deborah ask Skloot to promise she would do?
3. Explain the significance of the gift that Skloot delivered to Deborah at their first meeting.
4. What did Deborah hope would happen as a result of Skloot's research about Henrietta?
5. What effect did sensationalized journalism and fiction about HeLa and cell cloning have on Deborah? Do you think this was the response that the writers intended?
6. What information about her mother was Deborah unwilling to share with Skloot? Why do you think she was so protective of this information?

Chapter Thirty: Zakariyya

1. Why wasn't Skloot excited about meeting Zakariyya?
2. What does Zakariyya's choice of words—"that damn doctor who done rape her cells"—reveal about his feelings about and perception of what Gey did?
3. Describe your first impression of Zakariyya.
4. What does Deborah do that illustrates that she has a great sense of humor?
5. 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?
6. What does Zakariyya believe about his birth?
7. When Skloot met Sonny and Lawrence, they expressed a belief that the medical advances made possible by their mother's cells are "a miracle." How do Zakariyya's beliefs differ from those of his brothers?
8. 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.
9. What does Zakariyya blame on Henrietta's cancer cells? Does Deborah agree with him?
10. 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 Thirty-One: Hela, Goddess of Death

1. What does Deborah say about people who frame her mother's story as a story about racism?
2. Contrast the experience Henrietta's great-grandchildren, Alfred and Davon, have at the Maryland Science Center with the experience Deborah, Sonny, and Lawrence had growing up.

• guided reading and discussion questions (continued)

3. How did Skloot finance the research for her book? What did she promise to do for the Lacks family if and when the book was published?
4. Explain why it would be easy to believe that the Marvel super villain, Hela, Goddess of Death, was based on Henrietta Lacks.
5. Describe the relationship between Deborah and her grandson Davon.
6. Who is Franklin Salisbury Jr., and why did he contact Deborah?
7. Why did Deborah decide to go see her mother's cells? What obstacle almost kept her from doing so?

Chapter Thirty-Two: "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 is Lengauer's attitude toward the HeLa contamination problem? What belief of Deborah's does his attitude affirm?
4. Describe the way that Deborah and Zakariyya interact with their mother's cells.
5. What important misunderstanding about HeLa does Lengauer clarify for Deborah?
6. What does Lengauer believe about the Lackses' right to be financially compensated for the sale of their mother's cells?
7. Why do you think Deborah tells Skloot that she "just witnessed a miracle"?

Chapter Thirty-Three: 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. Compare the connotations of the name "Crownsville" with the name "Hospital for the Negro Insane." What do you think the directors were trying to achieve when they renamed the facility?
3. Why did Deborah and Skloot travel to Crownsville?
4. Why was Skloot surprised by the appearance of Crownsville? What do you think she expected to find?
5. Who is Paul Lurz? Which comments of his foreshadow that something terrible happened to Elsie?
6. Why were the hospital's medical records from the 1950s and earlier disposed of?
7. 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?
8. Skloot carefully describes the photograph of Elsie. What specific things can you infer about Elsie's treatment based on the description of the photograph?
9. How does Deborah demonstrate that she is in control when her right to view Elsie's records is questioned?

• guided reading and discussion questions (continued)

10. Describe conditions at the hospital during the time period when Elsie was a patient there.
11. Compare and contrast the medical research likely performed on Elsie with Gey's research and Southam's research. Does some medical research seem "more wrong"? Why do you think you feel that way?
12. What does Deborah's comment to Lurz that "if you gonna go into history, you can't do it with a hate attitude" tell you about the type of person she is?
13. How did Deborah initially react to the news about her sister? How did her reaction evolve after she had a chance to dwell on the picture and process the disturbing information that she had been given?
14. Skloot ends this chapter with Deborah deciding to finally give her access to Henrietta's medical records. Explain why this moment is significant.

Chapter Thirty-Four: The Medical Records

1. How does Deborah respond when Skloot suggests photocopying some of Henrietta's records? Why do you think she responds this way?
2. How can you tell that Elsie's photograph and autopsy are deeply troubling to Deborah?
3. What causes the confrontation between Deborah and Skloot? How is it resolved?
4. What reason does Deborah give for not wanting Skloot to type out Henrietta's records word-for-word?
5. Why do you think Deborah breaks out in hives after visiting Crownsville and giving Skloot access to the medical records?

Chapter Thirty-Five: 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 Thirty-Six: 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?

• guided reading and discussion questions (continued)

Chapter Thirty-Seven: “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?
4. Explain how Davon’s heroic actions saved Deborah’s life.
5. What obstacle kept Deborah from realizing her dream of returning to school?
6. What did Pullum ask Skloot to “preach” about at JaBrea’s baptism?
7. According to Deborah and Pullum, how is Henrietta’s story going to be different for Henrietta’s great-grandchildren and future generations?

Chapter Thirty-Eight: 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 great-great-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.

• writing prompts

LANGUAGE ARTS

1. Skloot begins the book with the following quote from Elie Wiesel: “We must not see any person as an abstraction. Instead, we must see in every person a universe with its own secrets, with its own treasures, with its own sources of anguish, and with some measure of triumph.” Analyze the book in light of this quote. Explain the various ways in which both the scientific community and the media are guilty of having viewed Henrietta and her family as abstractions. What are the consequences of this perspective? How is Skloot’s different perspective evident in the way she conducted her research and wrote the book?
2. Analyze the ways in which Skloot’s style exemplifies the writer’s rule of “show, don’t tell” as she develops the characters of Henrietta, Deborah, George Gey, or other key figures in the book. In your analysis, make sure to reference specific revealing passages.
3. The narrative arc involving Deborah and Skloot follows that of an archetypal hero journey. Analyze the story as a hero journey with Skloot as the hero, and then change your perspective and analyze the story with Deborah as the hero. (Note: A fruitful debate could be organized with half the class proposing that the book be read as Skloot’s hero journey, and half proposing that the book should be interpreted as Deborah’s journey.)
4. Skloot ends the book with a quote from Deborah about immortality. In the case of HeLa, there is literal immortality, but Deborah’s quote raises questions about spiritual immortality as well. In classic and contemporary literature, what does it mean to be “immortal”? Analyze the various ways that Henrietta and Deborah achieve immortality.
5. Analyze the significance of chapter and section breaks in the book. How does Skloot use transitions to develop continuity between sections that do not appear in chronological order? What is Skloot revealing through the juxtaposition of scenes and the division of the book into the three sections of Life, Death, and Immortality?

SOCIAL STUDIES

1. When Henrietta’s story first appeared in the mainstream media in 1976, many viewed it as one of race and racism. Evaluate whether or not you think this is an appropriate way to interpret the story. How do you think public interpretation might have been different if the story had been published at the time of Henrietta’s death in 1951? How is it being interpreted now? Analyze the cultural and historic events that have influenced, or would influence, these interpretations.
2. 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.” How does cultural perspective influence the way history is recorded, taught, and studied? Why is it important to approach history from an objective point of view? Why is this approach sometimes difficult?
3. Although a right to privacy is not explicitly mentioned in the Constitution, the Supreme Court has established that it is inherently protected by the Constitution. Explain the numerous ways that the Lacks family’s right to privacy was violated. Discuss the importance of the right to privacy. How has this right evolved over the course of American history? How is it being challenged by emergent technologies? How have groups of people such as African Americans, women, children, and most recently, immigrants, fought for legislation protecting their right to privacy? Cite specific court cases and/or current events.

• writing prompts (continued)

4. Turner Station is a classic example of a company town. Using the history of Turner Station as a model, discuss the role that the oil, automotive, steel, and coal industries have played, and continue to play, in shaping the landscape of the United States. Focus your discussion on the economic, environmental, and long-term public health implications for local communities resulting from the presence of these industries.
5. One of the important issues raised by Skloot's book is the ethics of journalism. What constitutes ethical journalism? Compare the differences between irresponsible and responsible reporting on HeLa and the Lacks family. What are some of the intended and unintended consequences of irresponsible journalism?

SCIENCE

1. In the Afterword, Skloot summarizes the main issues and legislation surrounding the collection and use of human tissue samples. Using her summary as an outline, examine the evolution of laws concerning tissue research and write a persuasive paper on the issue of whether or not people should be given legal ownership of, and/or control over, their tissues.
2. Discuss the historical and contemporary influence that journalists writing about science have had on public perception and understanding of the subject. Why do you think science reporting is often sensationalized? Why is it important for science reporting to be accessible? How has fear or lack of understanding influenced public policy relating to science?
3. There is often a tension between religious faith and science. Explore the importance of both religious faith and scientific understanding in the lives of the Lacks family. How does religious faith help frame the Lackses' response to, and interpretation of, the scientific information they receive about HeLa? How does Skloot's attitude toward the relationship between religious faith and science evolve as a result of her relationship with the Lacks family?
4. Using the book as a guide, describe the process of scientific inquiry. Examine the often contradictory forces of altruism and profit as they influenced research related to HeLa. What are the risks and benefits of allowing profit to guide research? What are the obstacles involved with conducting research purely for altruistic reasons?
5. Create a time line that begins with the removal of Henrietta's tissue sample and traces the scientific and medical breakthroughs that have been made possible as a result of HeLa cells. Explain how HeLa cells were used in each situation.

• topics for further discussion

1. The narrative structure of the book is quite complex, as the author weaves together numerous narratives. To develop this structure, Skloot used both works of fiction and films as models, and lists the novel *Fried Green Tomatoes at the Whistle Stop Cafe* and the film *Hurricane* as sources of inspiration as she organized her own book. Analyze the book's structure by comparing it to a work of fiction or a film that uses the structure of a frame narrative.
2. The television show *Law & Order* produced an episode titled "Immortal" that closely parallels many aspects of Skloot's book. Compare the similarities between the fictionalized *Law & Order* episode and the true story of the Lacks family. Contrast the rhetorical structure and narrative strategies used in the television episode with those in Skloot's book. Discuss the ethical implications of, and inherent irony in, the way the television episode presented the story, in light of the fact that neither Skloot nor any member of the Lacks family was consulted about or credited by the producers of the episode.
3. After getting out of jail, Zakariyya Rahman participates in a number of research studies in exchange for monetary compensation. Research the laws and the ethical debate over offering payment in exchange for participation in scientific studies, or for the donation of blood, eggs, sperm, or other biological materials. Do people have a right to "sell" their body, tissues, or organs if they wish? What ethical dilemmas could result from financially compensating "donors" and research participants? At what point could compensation become coercive?
4. Investigate the history of mental institutions in the United States. Explore the role that journalists have played in influencing public attitudes toward the mentally ill, and altering how the mentally ill are diagnosed and treated.
5. One of the arguments against giving people legal ownership of their tissues is summarized in the following quote from David Korn, vice provost for research at Harvard University: "I think people are morally obligated to allow their bits and pieces to be used to advance knowledge to help others. Since everybody benefits, everybody can accept the small risks of having their tissue scraps used in research." However, in a profit-driven health care system, all citizens do not have equal access to the treatments and medications made possible by tissue and cell research. What are the intended and unintended consequences of a profit-driven health care system?
6. Research the history of scientific experimentation on humans in the United States. What types of experiments have been done, and how did researchers find test subjects? Why did scientists find it necessary to conduct research on human beings? How did the development of HeLa cells change the way research could be conducted? What attempts (e.g. Nuremberg) have been made to govern the way this research is conducted, and how successful have these attempts been?
7. Study recent legal disputes over the collection and use of tissue samples. Specific cases to consider include the lawsuit filed by the Havasupai tribe against Arizona State University, the lawsuit filed by Texas parents over the collection of blood samples from their newborn children, and the controversy over the University of California at Berkeley's request that incoming freshman submit DNA samples.

• other titles of interest

I Know Why the Caged Bird Sings by Maya Angelou

Ten Days in a Mad-House by Nellie Bly

The Speckled Monster: A Historical Tale of Battling the Smallpox Epidemic
by Jennifer Lee Carrell

Remembering Jim Crow: African Americans Tell About Life in the Segregated South
Edited by William Chafe, Raymond Gavins, and Robert Korstad

Fried Green Tomatoes at the Whistle Stop Cafe by Fannie Flag

The Immortalists: Charles Lindbergh, Dr. Alexis Carrel, and Their Daring Quest to Live Forever
by David M. Friedman

Bad Blood: The Tuskegee Syphilis Experiment by James H. Jones

The Right to Privacy by Ellen Alderman and Caroline Kennedy

In The Name of Eugenics: Genetics and the Uses of Human Heredity by Daniel Kevles

The John McPhee Reader by John McPhee and William Howarth

Polio: An American Story by David M. Oshinsky

The Lives They Left Behind: Suitcases from a State Hospital Attic
by Darby Penny, Peter Stastny, Lisa Rinzler, and Robert Whitaker

Genie: A Scientific Tragedy by Russ Rymer

Coal River by Michael Shnayerson

Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present by Harriet A. Washington

The Plutonium Files: America's Secret Medical Experiments in the Cold War by Eileen Welsome

• online resources

Author Web site: <http://rebeccaskloot.com/>

Lacks family Web site: <http://www.lacksfamily.com/>

Radiolab segment on the story of Henrietta Lacks and her children, featuring audio footage of Deborah Lacks talking about her mother's cells, and actual recordings of key scenes from the book: <http://www.wnyc.org/shows/radiolab/episodes/2010/05/07/segments/150681>

Fresh Air's Terry Gross interviews the author:

<http://www.npr.org/templates/story/story.php?storyId=123232331>

CBS Sunday Morning piece featuring interviews with the author, members of the Lacks family, and a representative from Johns Hopkins:

<http://www.cbsnews.com/video/watch/?id=6304949n&tag=related:photovideo>

Tavis Smiley interviews the author:

http://www.pbs.org/kcet/tavissmiley/archive/201005/20100514_skloot.html

"Are We Alone?" public radio segment focusing on the science of HeLa cells:

http://radio.seti.org/episodes/Cell_Cell_

Author appearance on *The Colbert Report*: <http://www.colbertnation.com/the-colbert-report-videos/267542/march-16-2010/rebecca-skloot>

Slate article about the *Law & Order* episode based on the book:

<http://www.slate.com/id/2257189>

• ***The Immortal Life of Henrietta Lacks* and Common Core State Standards**

With appropriate scaffolding, *The Immortal Life of Henrietta Lacks* will meet the standard for **Range of Reading and Level of Text Complexity** for most high school grade levels. Schools are encouraged to adopt the text at the grade level where it best fits with ELA, science and/or social studies curriculum.

The questions and activities in the teaching guide for *The Immortal Life of Henrietta Lacks* were written to support standards-based instruction and are directly linked to many of the Common Core State Standards for ELA, Science, and Social Studies. The primary areas of connection are in the ELA standards for **Reading: Informational Texts** for grades 9-12 and in the literacy standards for **Key Ideas and Details** and **Craft and Structure** in History/Social Studies and Science/Technical Subjects. A complete list of the Common Core State Standards can be found at <http://www.corestandards.org/the-standards> . A list of primary standards addressed in the guide can be found below:

• **Common Core Standards English Language Arts 9-10:**

Key Ideas and Details

- Cite strong and thorough textual evidence to support analysis of what the text says explicitly as well as inferences drawn from the text.
- Determine a central idea of a text and analyze its development over the course of the text, including how it emerges and is shaped and refined by specific details; provide an objective summary of the text.
- Analyze how the author unfolds an analysis or series of ideas or events, including the order in which the points are made, how they are introduced and developed, and the connections that are drawn between them.

Craft and Structure

- Determine the meaning of words and phrases as they are used in a text, including figurative, connotative, and technical meanings; analyze the cumulative impact of specific word choices on meaning and tone (e.g., how the language of a court opinion differs from that of a newspaper).
- Analyze in detail how an author's ideas or claims are developed and refined by particular sentences, paragraphs, or larger portions of a text (e.g., a section or chapter).

• Common Core Standards English Language Arts 11-12:

Key Ideas and Details

- Cite strong and thorough textual evidence to support analysis of what the text says explicitly as well as inferences drawn from the text, including determining where the text leaves matters uncertain.
- Determine two or more central ideas of a text and analyze their development over the course of the text, including how they interact and build on one another to provide a complex analysis; provide an objective summary of the text.
- Analyze a complex set of ideas or sequence of events and explain how specific individuals, ideas, or events interact and develop over the course of the text.

Craft and Structure

- Determine the meaning of words and phrases as they are used in a text, including figurative, connotative, and technical meanings; analyze how an author uses and refines the meaning of a key term or terms over the course of a text (e.g., how Madison defines faction in Federalist No. 10).
- Analyze and evaluate the effectiveness of the structure an author uses in his or her exposition or argument, including whether the structure makes points clear, convincing, and engaging.
- Determine an author's point of view or purpose in a text in which the rhetoric is particularly effective, analyzing how style and content contribute to the power, persuasiveness or beauty of the text.

• Literacy in History/Social Studies and Science: Anchor Standards

Key Ideas and Details

- Read closely to determine what the text says explicitly and to make logical inferences from it; cite specific textual evidence when writing or speaking to support conclusions drawn from the text.
- Determine central ideas or themes of a text and analyze their development; summarize the key supporting details and ideas.
- Analyze how and why individuals, events, or ideas develop and interact over the course of a text.

Craft and Structure

- Interpret words and phrases as they are used in a text, including determining technical, connotative, and figurative meanings, and analyze how specific word choices shape meaning or tone.
- Analyze the structure of texts, including how specific sentences, paragraphs, and larger portions of the text (e.g., a section, chapter, scene, or stanza) relate to each other and the whole.
- Assess how point of view or purpose shapes the content and style of a text.

• Literacy in Science and Technical Subjects Grades 9-10

Key Ideas and Details

- Cite specific textual evidence to support analysis of science and technical texts, attending to the precise details of explanations or descriptions.
- Determine the central ideas or conclusions of a text; trace the text's explanation or depiction of a complex process, phenomenon, or concept; provide an accurate summary of the text.

Craft and Structure

- Determine the meaning of symbols, key terms, and other domain-specific words and phrases as they are used in a specific scientific or technical context relevant to grades 9–10 texts and topics.
- Analyze the author's purpose in providing an explanation, describing a procedure, or discussing an experiment in a text, defining the question the author seeks to address.

• Literacy in Science and Technical Subjects Grades 11-12

Key Ideas and Details

- Cite specific textual evidence to support analysis of science and technical texts, attending to important distinctions the author makes and to any gaps or inconsistencies in the account.
- Determine the central ideas or conclusions of a text; summarize complex concepts, processes, or information presented in a text by paraphrasing them in simpler but still accurate terms.

Craft and Structure

- Determine the meaning of symbols, key terms, and other domain-specific words and phrases as they are used in a specific scientific or technical context relevant to grades 11–12 texts and topics.
- Analyze the author's purpose in providing an explanation, describing a procedure, or discussing an experiment in a text, identifying important issues that remain unresolved.

• about this guide's writer

Amy Jurskis holds a BA in English from the University of Georgia and an MAT from Agnes Scott College. She is the department chair for language arts at Tri-Cities High School, an urban public high school in southwest Atlanta.

• cast of characters

Immediate Lacks Family

David “Day” Lacks—Henrietta’s husband and cousin
David Jr. “Sonny” Lacks—Henrietta and Day’s third child

Deborah “Dale” Lacks—Henrietta and Day’s fourth child

Elsie Lacks (born Lucille Elsie Pleasant)—Henrietta’s second born and eldest daughter. She was institutionalized due to epilepsy and died at age 15.

Eliza Lacks Pleasant—Henrietta’s mother. She died when Henrietta was four.

Gladys Lacks—Henrietta’s sister, who disapproved of Henrietta’s marriage to Day

Johnny Pleasant—Henrietta’s father. He left his ten children when their mother died.

Lawrence Lacks—Henrietta and Day’s firstborn child

Loretta Pleasant—Henrietta’s birth name

Tommy Lacks—Henrietta and Day’s grandfather who raised both of them

Zakariyya Bari Abdul Rahman (born Joe Lacks)—Henrietta and Day’s fifth child. Henrietta was diagnosed with cervical cancer shortly after his birth.

Extended Lacks Family

Albert Lacks—Henrietta’s white great-grandfather. He had five children by a former slave named Maria and left part of the Lacks plantation to them. This section became known as “Lacks Town.”

Alfred “Cheetah” Carter—Deborah’s first husband. The marriage was abusive and ended in divorce.

Alfred Jr.—Deborah and Cheetah’s firstborn child and Little Alfred’s father

Bobette Lacks—Lawrence’s wife. She helped raise Lawrence’s siblings after Henrietta’s death, and advocated for them when she discovered they were being abused.

Cliff Garret—Henrietta’s cousin. As children, they worked the tobacco fields together.

“Crazy Joe” Grinnan—Henrietta’s cousin who competed unsuccessfully with Day for her affection

Davon Meade—Deborah’s grandson who often lived with and took care of her

Ethel—Galen’s wife, an abusive caregiver to Henrietta’s three youngest children

Fred Garret—Henrietta’s cousin who convinced Day and Henrietta to move to Turner Station

Galen—Henrietta’s cousin. He and his wife, Ethel, moved in with Day after Henrietta’s death to help take care of the children. He ended up abusing Deborah.

Gary Lacks—Gladys’s son and Deborah’s cousin. A lay preacher, he performed a faith healing on Deborah.

LaTonya—Deborah and Cheetah’s second child; Davon’s mother

“Little Alfred”—Deborah’s grandson

Margaret Sturdivant—Henrietta’s cousin and confidante. Henrietta went to her house after radiation treatments at Johns Hopkins.

Reverend James Pullum—Deborah’s second ex-husband, a former steel-mill worker who became a preacher

Sadie Sturdivant—Margaret’s sister, Henrietta’s cousin and confidante, she supported Henrietta during her illness. She and Henrietta sometimes sneaked out to go dancing.

Members of the Medical and Scientific Community

Alexis Carrel—French surgeon and Nobel Prize recipient who claimed to have cultured “immortal” chicken-heart cells

Chester Southam—cancer researcher who conducted unethical experiments to see whether or not HeLa could “infect” people with cancer

Christoph Lengauer—cancer researcher at Johns Hopkins who helped develop FISH, a technique used to detect and identify DNA sequences, and who reached out to members of the Lacks family

Emanuel Mandel—director of medicine at the Jewish Chronic Disease Hospital (JCDH) who partnered with Southam in unethical experiments

Dr. George Gey—head of tissue-culture research at Johns Hopkins. He developed the techniques used to grow HeLa cells from Henrietta’s cancer tissue in his lab.

Howard Jones—Henrietta’s gynecologist at Johns Hopkins

Leonard Hayflick—Microbiologist who proved that normal cells die when they’ve doubled about fifty times. This is known as the Hayflick limit.

Margaret Gey—George Gey’s wife and research assistant. She was trained as a surgical nurse.

Mary Kubicek—George Gey’s lab assistant who cultured HeLa cells for the first time

Richard Wesley TeLinde—one of the top cervical cancer experts in the country at the time of Henrietta’s diagnosis. His research involved taking tissue samples from Henrietta and other cervical cancer patients at Johns Hopkins.

Roland Pattillo—professor of gynecology at Morehouse School of Medicine who was one of George Gey’s only African-American students. He organizes a yearly HeLa conference at Morehouse in Henrietta’s honor.

Stanley Gartler—the geneticist who dropped the “HeLa bomb” when he proposed that many of the most commonly used cell cultures had been contaminated by HeLa

Susan Hsu—the postdoctoral student in Victor McKusick’s lab who was assigned to make contact with the Lackses and request samples from them for genetic testing without informed consent

Victor McKusick—geneticist at Johns Hopkins who conducted research on samples taken from Henrietta’s children without informed consent to learn more about HeLa cells

Walter Nelson-Rees—the geneticist who tracked and published the names of cell lines contaminated with HeLa without first warning the researchers he exposed. He became known as a vigilante.

Journalists and Others

Courtney “Mama” Speed—resident of Turner Station and owner of Speed’s Grocery. She organized an effort to build a Henrietta Lacks museum.

John Moore—cancer patient who unsuccessfully sued his doctor and the regents of the University of California over the use of his cells to create the Mo cell line

Michael Gold—author of *A Conspiracy of Cells*. He published details from Henrietta’s medical records and autopsy report without permission from the Lacks family.

Michael Rogers—*Rolling Stone* reporter who wrote an article about the Lacks family in 1976. He was the first journalist to contact the Lackses.

Sir Lord Keenan Kester Cofield—attempted to sue Johns Hopkins and the Lacks family

Ted Slavin—a hemophiliac whose doctor told him his cells were valuable. Slavin founded Essential Biologicals, a company that sold his cells, and later cells from other people so individuals could profit from their own biological materials.

• timeline

1889 Johns Hopkins Hospital is founded.

1912 Alexis Carrel claims to have successfully grown immortal chicken-heart cells.

1920 Henrietta Lacks is born in Roanoke, Virginia.

1947 The Nuremberg Code, a set of ethical standards for human experimentation, is produced as the result of a trial against several Nazi doctors who conducted experiments on prisoners during WWII.

1951 George Gey successfully cultures the first immortal human cell line using cells from Henrietta's cervix. It is given the name HeLa after the first two initials of Henrietta's first and last names.

1951 Henrietta Lacks dies of an unusually aggressive strain of cervical cancer.

1952 HeLa cells become the first living cells shipped via postal mail.

1952 The Tuskegee Institute opens the first "HeLa factory," supplying cells to laboratories and researchers and operating as a nonprofit. Within a few years, a company named Microbiological Associates would begin selling HeLa for profit.

1952 Scientists use HeLa cells to help develop the polio vaccine.

1953 HeLa cells become the first cells ever cloned.

1954 The pseudonym "Helen Lane" first appears in print as the source of HeLa cells.

1954 Chester Southam begins to conduct experiments without patient consent to see whether or not injections of HeLa cells could cause cancer.

1957 The term "informed consent" first appears in court documents.

1965 HeLa cells are fused with mouse cells, creating the first animal-human hybrid cells.

1965 The Board of Regents of the University of the State of New York finds Southam and a colleague guilty of unprofessional conduct and calls for stricter guidelines regarding human research subjects and informed consent.

1966 To ensure adherence to the new guidelines for research involving human subjects, the National Institutes of Health begins requiring the approval of Institutional Review Boards for any research they fund.

1966 Gartler drops the "HeLa Bomb" and proposes that HeLa cells have contaminated numerous cell lines.

1970 George Gey dies of pancreatic cancer.

1971 In a tribute to Gey, Henrietta Lacks is correctly identified for the first time in print as the source of HeLa.

1973 The Lacks family learns for the first time that Henrietta's cells are still alive.

1973 Researchers from Johns Hopkins take samples from Henrietta's children to further HeLa research, without informed consent.

1974 The Federal Policy for the Protection of Human Subjects (the Common Rule) requires informed consent for all human-subject research.

1975 Michael Rogers publishes an article about HeLa and the Lacks family in *Rolling Stone*. The Lacks family learns for the first time that Henrietta's cells have been commercialized.

1984 John Moore unsuccessfully sues his doctor and the Board of Regents of the University of California for property rights over his tissues. Moore appeals the decision.

1985 Portions of Henrietta's medical records are published without her family's knowledge or consent.

1988 The California Court of Appeals rules in John Moore's favor, saying that patients must have the power to control what becomes of their own tissues. Moore's doctor and the University of California appeal.

1991 The Supreme Court of California rules against John Moore, saying that once tissues are removed from the body, with or without consent, a person no longer owns those tissues.

1996 The Health Insurance Portability and Accountability Act makes it illegal for healthcare providers or health insurers to make personal medical information public.

1999 The RAND Corporation publishes a report with a "conservative estimate" that more than 307 million tissue samples from more than 178 million people are stored in the United States alone. The majority of the samples were taken without consent.

2005 Members of the Native American Havasupai tribe sue Arizona State University after scientists take tissue samples the tribe donated for diabetes research and use them without consent to study schizophrenia and inbreeding.

2005 Six thousand patients join a lawsuit against Washington University, demanding that the university remove their tissue samples from its prostate cancer bank. Two courts later rule against the patients.

2005 By this date, the U.S. government has issued patents relating to the use of about 20 percent of known human genes, including genes for Alzheimer's, asthma, colon cancer, and, most famously, breast cancer.

2006 An NIH researcher is charged with violating a federal conflict-of-interest law for providing thousands of tissue samples to the pharmaceutical company Pfizer in exchange for about half a million dollars.

2009 The National Institutes of Health invests \$13.5 million to develop a bank for fetal blood samples.

2009 Parents in Minnesota and Texas sue to stop the nationwide practice of storing and conducting research—without consent—on fetal blood samples, many of which can be traced back to the infants they came from.

2009 More than 150,000 scientists join the American Civil Liberties Union and breast cancer patients in suing Myriad Genetics over its breast cancer gene patents. The suit claims that the practice of gene patenting violates patent law and has inhibited scientific research.



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