

# Southfield Public Library

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## *The Immortal Life of Henrietta Lacks by Rebecca Skloot*

*Discussion questions used at SPL -- October 2011*

1. Was it important for the author to use the voices of the people she interviewed . . . using dialect/language to portray those voices?
2. Did that technique, using people's words and voices to recall events, make the book more readable? More believable? Could you see it done a different way?
3. What were some of the big issues in this book for you? Ethics. . . Do your body parts belong to you once they are taken out? Fairness . . . is life fair? Discrimination . . . do you think Henrietta got the same care as a poor white woman? A well off any color woman? Faith . . . poverty, patient privacy . . .
4. Why do you think the author was so determined to write this book . . . why didn't she get discouraged with the so many brick walls she ran into?
5. How did she do explaining the science of cells and their use to the reader? Did the author re-create Henrietta for you? What sort of person was she?
6. What did you think of daughter Deborah's thinking about how her mother did so much for medicine and the children of HeLa couldn't afford to go to a doctor?
7. Why did Henrietta keep her cancer a secret? Do you think the doctors missed the tumor during the birth of her last baby? Or did it grow that quickly?
8. After her treatments, things looked positive for Henrietta, but things quickly turned south. Again, do you think her doctors were neglectful or could it have had something to do with the way her cells survived in the laboratory?
9. What did you think of the communication between Henrietta and her doctors . . . It appeared that she didn't know that she would become barren or that the final treatments were merely to alleviate pain . . . What do you think was missing there?
10. Have doctor/patient relationships changed over the years? Do we still treat them as all knowing, all powerful people? Do you think poor people are still treated differently?
11. When the author was warned about how to act around Deborah . . . p. 51 . . . what kind of person were you expecting? When you read that first phone conversation with Deborah, what did you think then? What sort of person was Deborah? As you read more of her story, how did you feel about her?

12. What's your opinion on researcher Gey visiting Henrietta . . . Do you think he did? On p. 103 it shows that Gey was unhappy about the way other scientists were using HeLa cells . . . did it seem as though he thought they belonged to him? Did they?
13. Did the good that Henrietta's cells did for the world, from health to economic to scientific breakthroughs, make up for the way she was treated?
14. Why were the scientists upset when the cells were traced back to Henrietta?
15. There was much in the early part of the book about how the family never knew about Henrietta's cells . . . If you were in their shoes, would it be important to you? What would you want to know . . . would you want financial compensation? Would you feel a sense of violation when you did find out?
16. Which part was more interesting to you . . . The story of Henrietta or of her cells?
17. How much science did you learn? Was it important to the story that information about cells and their biology was incorporated into the book?
18. How would you characterize the Lacks family? Why do you think they felt the way they did about their mother and her cells?
19. How much did you know about people being used as research subjects, with or without their consent . . . Do you think it still goes on today? Do you read all the papers you sign at the doctors?
20. On p. 130, there is discussion on testing on humans by a doctor injecting people with cancer cells. Some were prisoners, some ob/gyn patients . . . what did you think of his attitude?
21. In your opinion, what was the most appalling treatment of the Lacks family by medical personnel over the years?
22. What were the differences between the other cell donors that the author talked about? Should people be able to profit from their own cells? Should doctors or corporations?
23. Do you think Henrietta would have given consent to let her cells be used?
24. How do you think Henrietta's family reacted to the Skloot's book? Would they have been pleased with her portrayal?
25. Why was it important to Deborah for her mother to be as famous as her cells were? Do you think she finally is?
26. Do you agree with the Lacks' family desire to be compensated for Henrietta's cells? Or for participating in the book? Did the author have any responsibility to do so? Does any author?
27. Do you think this book makes a case for universal health care?

28. What do you think the author had in mind to accomplish with this book? Did she? Did she help make the life of the Lacks family any better?

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## *General discussion questions*

- For the person who chose the book – What made you want to read it? What made you pick it for the book club? Did it live up to your expectations?
- How is the book structured? First person? Third person? Flashbacks? Narrative devices? Do you think the author did a good job with it?
- How would you describe the author’s writing style? Concise? Flowery? How is language used in this book? Read aloud a passage that really struck you. How does that passage relate to the book as a whole?
- How effective is the author’s use of plot twists? Were you able to predict certain things before they happened? Did the author keep you guessing until the end?
- Did the book hold your interest?
- How important is the setting to the story? Did you feel like you were somewhere else? Did the time setting make a difference in the story? Did the author provide enough background information for you to understand the setting and time placement?
- Which is stronger in the book – the characters or the plots?
- Would you recommend this book to someone else? Why? And to whom?

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## *The Immortal Life of Henrietta Lacks*

Questions taken from the author's website

<http://rebeccaskloot.com/>

1. On page xiii, Rebecca Skloot states, "This is a work of nonfiction. No names have been changed, no characters invented, no events fabricated." Consider the process Skloot went through to verify dialogue, re-create scenes, and establish facts. Imagine trying to re-create scenes such as when Henrietta discovered her tumor (page 15). What does Skloot say on pages xiii–xiv and in the notes section (page 346) about how she did this?
2. One of Henrietta's relatives said to Skloot, "If you pretty up how people spoke and change the things they said, that's dishonest" (page xiii). Throughout, Skloot is true to the dialect in which people spoke to her: The Lackses speak in a heavy Southern accent, and Lengauer and Hsu speak as nonnative English speakers. What impact did the decision to maintain speech authenticity have on the story?
3. As much as 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?
4. In a review for the New York Times, Dwight Garner writes, "Ms. Skloot is a memorable character herself. She never intrudes on the narrative, but she takes us along with her on her reporting." How would the story have been different if she had not been a part of it? What do you think would have happened to scenes like the faith healing on page 289? Are there other scenes you can think of where her presence made a difference? Why do you think she decided to include herself in the story?
5. Deborah shares her mother's medical records with Skloot but is adamant that she not copy everything. On page 284 Deborah says, "Everybody in the world got her cells, only thing we got of our mother is just them records and her Bible." Discuss the deeper meaning behind this statement. Think not only of her words, but also of the physical reaction she was having to delving into her mother's and sister's medical histories. If you were in Deborah's situation, how would you react to someone wanting to look into your mother's medical records?
6. 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, and Immortality. How would the story have been different if it were told chronologically?
7. As a journalist, Skloot is careful to present the encounter between the Lacks family and the world of medicine without taking sides. Since readers bring their own experiences and opinions to the text, some may feel she took the scientists' side, while others may feel she took the

family's side. What are your feelings about this? Does your opinion fall on one side or the other, or somewhere in the middle, and why?

8. 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 anaesthetic 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 have given 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?
9. In 1976, when Mike Rogers's Rolling Stone article was printed, many viewed it as a story about race (see page 197 for reference). How do you think public interpretation might have been different if the piece had been published at the time of Henrietta's death in 1951? How is this different from the way her story is being interpreted today? How do you think Henrietta's experiences with the medical system would have been different had she been a white woman? What about Elsie's fate?
10. 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?
11. 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 no 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 even though they can't afford it? How would you respond if you were in their situation?
12. Dr. McKusick directed Susan Hsu to contact Henrietta's children for blood samples to further HeLa research; neither McKusick nor Hsu tried to get informed consent for this research. Discuss whether or not you feel this request was ethical. Further, think about John Moore and the patent that had been filed without his consent on his cells called "Mo" (page 201). How do you feel about the Supreme Court of California ruling that states when tissues are removed from your body, with or without your consent, any claim you might have had to owning them vanishes?
13. Religious faith and scientific understanding, while often at odds with each other, play important roles 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 religious faith and science evolve as a result of her relationship with the Lackses?
14. On page 261, Deborah and Zakariyya visit Lengauer's lab and see the cells for the first time. How is their interaction with Lengauer different from the previous interactions the family had

with representatives of Johns Hopkins? Why do you think it is so different? What does the way Deborah and Zakariyya interact with their mother's cells tell you about their feelings for her?

15. Reflect upon Henrietta's life: What challenges did she and her family face? What do you think their greatest strengths were?
16. Consider the progression of Henrietta's cancer in the last eight months between her diagnosis and death. How did she face death? What do you think that says about the type of person she was?