



The Immortal Life of Henrietta Lacks by

Rebecca Skloot

Acclaimed author Skloot brilliantly weaves together the story of Henrietta Lacks--a woman whose cells have been unwittingly used for scientific research since the 1950s--with the birth of bioethics, and the dark history of experimentation on African Americans.

About the Author: Rebecca Skloot is an award-winning science writer whose work has appeared in The New York Times Magazine; O, The Oprah Magazine; Discover; and many others. Skloot is the founder and president of <u>The Henrietta</u> <u>Lacks Foundation</u>. She has a B.S. in biological sciences and an MFA in creative nonfiction. She has taught creative writing and science journalism at the University of Memphis, the University of Pittsburgh, and New York University. She lives in Chicago. See the author's website: <u>www.rebeccaskloot.com</u> for

wonderful information about the author, the book, and the Lacks family. Included are photos and videos.

Discussion Questions:

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?

