

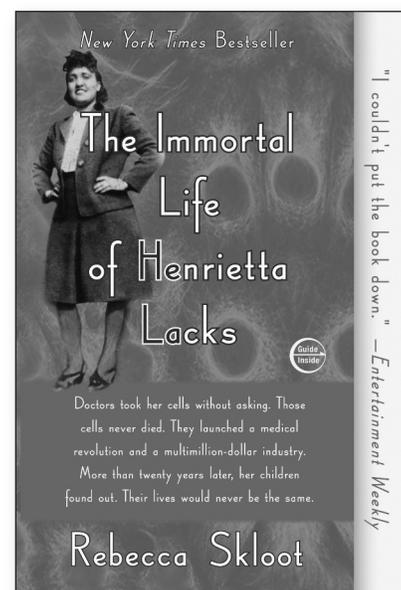


The Immortal Life of Henrietta Lacks

By Rebecca Skloot

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Broadway | TR | 978-1-4000-5218-9
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NOTE TO DISCUSSION FACILITATORS:

A casual remark by the instructor of an introduction to biology course at a community college sparked Rebecca Skloot's curiosity and inspired a research project that would take over a decade to complete: discovering the story of Henrietta Lacks and her family. Since little information about Henrietta Lacks existed at the time, Skloot had to turn to primary sources and personal interviews, and the result is an insightful look into Henrietta's life, death, and the subsequent "birth" of the immortal cell line HeLa.

In telling Henrietta's story, Rebecca Skloot explains how experiments involving HeLa have changed the landscape of scientific research. The book provides a platform for students to engage thoughtfully with complex moral and ethical dilemmas as it raises questions about research, informed consent, journalism, and the complexities of legislation regarding privacy and the ownership of biological materials.

Random House, Inc. Academic Dept. 1745 Broadway, New York, NY 10019

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• guided reading and discussion questions

1. Rebecca Skloot begins her 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. What do Skloot’s interactions with the Lacks family reveal about her intentional choice not to view them as abstractions? How could this quote be relevant to your perspective as you begin your collegiate studies?
2. One aspect of the book that readers often find fascinating is the section detailing the numerous medical advances that were made possible because of experimentation involving HeLa. Such advances include the development of vaccines, drugs to treat illnesses and diseases ranging from influenza to cancer, and treatments, such as in vitro fertilization, that have helped millions of people. Even Henrietta’s own children were prescribed medications that had been developed through the use of their mother’s cells. Everyone in the world has personally benefited from research on HeLa cells in some way (often many ways). Did learning about specific drugs and treatments developed through the use of HeLa help you make a personal connection to the story? How have you or your family members benefited personally from the medications or treatments Skloot mentions as having been developed using HeLa cells? If you had an opportunity to speak to the Lacks family about their mother’s contribution to medicine, what would you want to tell them?
3. Rebecca Skloot became interested in Henrietta’s story after an off-hand remark from a college instructor. When she began researching Henrietta Lacks, do you think she had any idea where the story would lead her? Why do you think she continued to pursue information about the Lacks family even after she met with resistance? Would you have been as tenacious as Skloot was? What can you learn from her experience? As you approach your college classes, how can you prepare yourself to be open to unexpected inspiration?
4. Very few secondary sources about Henrietta Lacks existed when Rebecca Skloot began searching for information about the woman behind HeLa. Carefully examine the endnotes, acknowledgements, and foreword of the book and discuss the various documents and interviews that Skloot used to research and write the story. Discuss the specific sources that enabled Skloot to factually document dialogue and recount descriptions of historical events and locations. What practical lessons can you learn about how to approach a research question when secondary sources are not readily available? In what specific ways could Skloot’s reliance on primary sources have influenced the way she told Henrietta’s story?
5. As you were reading the book, how did you initially react to George Gey? Did learning that he did not personally profit from the discovery or distribution of HeLa change your opinion of him? Did the section on Gey’s own battle with cancer change your opinion of him? Should it have? How much accountability should a person have if the results of their actions are damaging but their intent was good? How do you think Gey should be remembered?
6. Analyze the chain of events that led to Henrietta’s identity being successfully concealed. Do you think that doctors were right to conceal her identity for so long? How might the story of HeLa and the Lacks family have been different if Henrietta had been correctly identified and acknowledged shortly after her death? What role did journalists play in facilitating the release of Henrietta’s identity? Do you feel that the journalists that covered Henrietta’s story in the 1970’s and 1980’s breached any ethical principles in their reporting? How did the earlier stories (for example, the *Rolling Stone* article and the BBC documentary) impact Henrietta’s family? Contrast the way that earlier journalists interacted (or failed to interact) with the Lacks family with the way Rebecca

• guided reading and discussion questions (continued)

Skloot interacted with Henrietta's family. What do you think made Skloot's perspective and approach to telling Henrietta's story so different from the approach of earlier journalists? Using the "Where They Are Now" section at the end of the book as a starting point, discuss the impact that Skloot's research had on the Lacks family. What has this book taught you about the ethical principles that should guide research and/or journalism?

7. When Henrietta's story first appeared in the mainstream media in 1976, many viewed it as a story about race and racism. Do you feel that this is an appropriate interpretation? How do you think race, gender, and class influenced the events in the book and the circumstances of the Lacks family? In what ways might the story have been different if the first immortal cell line had been taken from someone of a different race, gender, or socioeconomic background?
8. 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 a person's cultural perspective influence the way history is recorded, taught, and studied? Why is it important to approach history from an objective point of view? What challenges to your objectivity do you think you might face as you study history as a college student? How will you maintain intellectual objectivity when faced with the study of historical events, people, or philosophies that might provoke in you a strong personal or emotional response?
9. Although a right to privacy is not explicitly mentioned in the Constitution, the Supreme Court has established that our personal privacy is inherently protected. Discuss the numerous ways that the Lacks family's right to privacy was violated. How important is the right to privacy? Are there ever times when you think sacrificing this right is justified or necessary? How could your right to privacy be challenged by emergent technologies? How does legislation need to evolve to ensure that the right to privacy is protected in the 21st century?
10. There is often a tension between religious faith and science, with many making the assumption that the two are mutually exclusive. Explore the importance of both religious faith and scientific understanding in the lives of the Lacks family. How did religious faith help frame the Lacks family's response to and interpretation of the scientific information they receive about HeLa? How did Skloot's attitude towards the relationship between religious faith and science evolve as a result of her relationship with the Lacks Family? Did the book challenge any of your beliefs about faith and science?
11. After getting out of jail, Zakariyya Lacks participates in a number of research studies in exchange for monetary compensation. College students are often targeted for participation in studies or for the donation of biological materials such as blood, sperm, or eggs. Consider the debate over paying people for their participation in research studies or for the donation of biological materials. Would you be more likely to participate in a research study if you were financially compensated? Do you believe that people have a right to "sell" their body, tissues or organs? What ethical dilemmas could potentially result from financially compensating "donors" and research participants? At what point could compensation become coercive?
12. 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." Do you believe that we have a moral or ethical responsibility to "offer" our biological materials for use and research by the medical community? How does the issue of profit complicate this

• guided reading and discussion questions (continued)

- argument? Under our current healthcare system, is it true that “everybody benefits” from the results of medical research?
13. The discovery of her sister Elsie’s medical records took a dramatic physical and emotional on Deborah Lacks. Do you think it would have been better if Elsie’s records had been destroyed with the other documentation from this disturbing time in Crownsville’s past? Do you believe we have a responsibility to preserve and document details surrounding chapters in American history that may be troubling or disturbing? If a similar situation had happened to a member of your family, how much information would you want to discover about what happened? What role should scholars and historians take in the documentation and preservation of recent history?
 14. Discuss the role of education in the book. How did learning about HeLa and their family’s history change the lives of Deborah and her brothers?
 15. To date, no member of the Lacks family has been compensated financially for the use of Henrietta’s cells. What factors could be inhibiting medical companies or research facilities from making a contribution in appreciation of Henrietta Lacks? Does the Lacks family deserve some sort of financial compensation? If not, why? If so, what do they deserve? How would you determine the amount of compensation owed to the family? Who should pay for this compensation? Is recognition of the significance of their mother’s contribution enough? If you were in the Lacks family’s position, would you try to pursue legal action?



• 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. She is co-editor of *The Best American Science Writing 2011* and has worked as a correspondent for NPR’s *Radiolab* and PBS’s *Nova ScienceNOW*. She was named One of Five Surprising Leaders of 2010 by the *Washington Post*. Skloot’s debut book, *The Immortal Life of Henrietta Lacks*, took more than a decade to research and write, and instantly became a *New York Times* best-seller. It was chosen as a best book of 2010 by more than 60 media outlets, including *Entertainment Weekly*, *People Magazine*, and *New York Times*. It is being translated into more than 25 languages, adapted into a young reader edition, and being made into an HBO film produced by Oprah Winfrey and Alan Ball. Skloot is the founder and president of The Henrietta Lacks Foundation. 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. For more information, visit her website at **RebeccaSkloot.com**, where you’ll find links to follow her on Twitter and Facebook.

Rebecca Skloot is available to speak at select college events.

Please contact the publisher for more information or visit her website at:

www.RebeccaSkloot.com

• about this guide’s writer

Amy Jurskis holds a M.A.T. degree 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. She has facilitated a vertical teaming initiative in the area of language arts, and she coordinates the summer reading program for Fulton County Schools.