

TJHSST One Book – 2011: *The Immortal Life of Henrietta Lacks*

Summer Reading Study Guide for Students and Parents

Why read *The Immortal Life of Henrietta Lacks*?

From a scientific point of view, few discoveries have made a more revolutionary and valuable contribution to the overall advancement in medical research than HeLa cells. From a humanistic point of view, the Lacks family represents thousands of families who strive to maintain their dignity as they suffer poverty, discrimination, and poor health. To fully appreciate the profundity of the medical advancement derived from Henrietta Lacks' cells, one needs to understand the personal story of the woman behind the cells. At some level we can all relate to the book's themes of familial love, despair brought on by loss, vulnerability in the face of illness, and the need to be heard and understood. It is this connection that helps us think beyond the mere science of HeLa and recognize the source of this medical miracle as a human being much like ourselves.

When the medical and personal ramifications of the HeLa cells are woven together, a clear moral and ethical dilemmas arise. It is our hope that you and your child will entertain these issues and become a member of the unique TJ community of readers, researchers, and scientists, by considering the TJ One Question* while reading *The Immortal Life of Henrietta Lacks* together this summer. With an in-depth parent/child discussion, the difficult portions of this book can enhance your child's understanding of the full story while evoking empathy for a family who misses their mother and wishes to honor her memory. These discussions will help pave the way for students to develop a discerning mind about blatant personal injustices as well as tackle the more subtle questions of ethics and morality in our scientific and social milieus.

*** TJ ONE QUESTION: How can we, the TJ community, take action to prepare students to confront difficult moral and ethical decisions, both now and in the future?**

Below is a series of questions and discussion points to help you and your family study the book.

Pre-reading Discussion Questions:

- Have you or anyone in your family felt vulnerable and afraid while being treated for a medical condition? What were some of the questions you had for the doctors and nurses? Were they answered in a way you understood? Were your fears and anxieties alleviated?
- If you knew that you could help advance medical research, would you be willing to donate some of your tissues and cells to researchers? How would you react if you didn't know some of your tissues and cells were being used for medical research?
- How would you feel if you learned that others were making money because you had donated (willingly or not) your tissues and cells?
- If you believed that you were treated differently and unfairly by doctors and hospital staff, what would you do? Can you remember a time when you worried that you were treated unfairly?

Take note of the following passages as you read through the text and then open up a dialogue with your child using the recommended discussion points:

Page 15: *“The public wards at Hopkins were filled with patients, most of them black and unable to pay their medical bills. David drove Henrietta nearly twenty miles to get there, not because they preferred it, but because it was the only major hospital for miles that treated black patients. This was the era of Jim Crow – when black people showed up at white-only hospitals, the staff was likely to send them away, even if it meant they might die in the parking lot. Even Hopkins, which did treat black patients, segregated them in colored wards, and had colored-only fountains.”*

Page 16: *“It was no surprise that [Henrietta] hadn't come back all those times for follow-up. For Henrietta, walking into Hopkins was like entering a foreign country where she didn't speak the language.”*

- Discuss how being segregated in “colored wards” might influence the actions and attitudes of a black patient? How might it influence the medical care?
- Research Jim Crow and discuss how this influenced society as a whole.

Page 63: *“This was a time when ‘benevolent deception’ was a common practice – doctors often withheld even the most fundamental information from their patients, sometimes not giving them any diagnosis at all. They believed it was best not to confuse or upset patients with frightening terms they might not understand, like cancer. Doctors knew best, and most patients didn't question that. Especially black patients in public wards.”*

- Discuss how the relationship between doctor and patient has changed since Henrietta was treated.
- Discuss “patient rights” as we understand them today. Consider your views on whether a doctor’s professional judgment should be questioned.

Pages 110 – 117: Chapter - *“Too Young to Remember”*

- Discuss why you think the author found the details about Deborah’s and Joe’s childhood important enough to include in the book, especially as it relates to the One Question.
- What do we learn about Joe and Deborah that might help us understand their actions later in the book?

Page 131: “ . . . on August 20, 1947, a U.S.-led war tribunal in Nuremberg, Germany, had sentenced seven Nazi doctors to death by hanging. Their crime was conducting unthinkable research on Jews without consent – sewing siblings together to create Siamese twins, dissecting people alive to study organ function.

“The tribunal set forth a ten-point code of ethics now known as the Nuremberg Code, which was to govern all human experimentation worldwide. The first line in that code says, ‘The voluntary consent of the human subject is absolutely essential.’ The idea was revolutionary.”

- Research the Nuremberg Code and Trials for more details about the war crimes referenced in the passage above.
- Discuss whether you think it is fair to make comparisons between the medical research derived from HeLa cells and those from Nazi doctors.
- Do you think it is right to have federal laws regulating human experimentation? How specific should these laws be?

Page 141: “. . . the public panicked as the media published one sensational headline after the next:

**Man-Animal Cells Are Bred in Lab . . . The Next Step
Could be Tree Men . . . Scientists Create Monsters**

- Discuss the role of media in reporting medical advancements.
- Should the public be apprised of all that medical research is achieving even when the results are not fully developed or complete?
- Does the media have an ethical responsibility to report medical advancements in a non-sensational way?

Pages 144 - 151: Chapter - *“The Most Critical Time on This Earth Is Now”*

“When Deborah was a junior in high school, at the age of sixteen, she got pregnant with her first child. Bobbette cried when she found out.”

- Discuss the circumstances that led Deborah to becoming a mother at an early age.
- Discuss the circumstances that led Joe to jail.
- Consider what life may have been like for Deborah if Bobbette had not watched out for her.
- Consider what life may have been like for Deborah and Joe if their mother had not died at such an early age.

Page 169: *“‘You know what is a myth?’ Bobbette snapped from the recliner. ‘Everybody always saying Henrietta lacks donated those cells. She didn’t donate nothing. They took them and didn’t ask.’ . . . ‘If Dr. Gey wasn’t dead, I think I would have killed him myself.’”*

- Discuss the anger that Henrietta’s family feels toward the doctor’s involved with the HeLa cells.
- If you learned that the cells came from one of your family members, how would you react?

Page 280: *“. . .Deborah had written definitions of scientific and legal terms, and poems about her life.”*

*cancer
check up
can’t afford
white and rich get it
my mother was black
black poor people don’t have the money to
pay for it
mad yes I am mad
me were used by taking our blood and lied to
We had to pay for our own medical, can you
relieve that.
John Hopkin Hospital and all other places,
that has my mother cells, don’t give her
Nothing.*

- Discuss what you learn about Deborah from this poem.
- Why do you think the author included this poem by Deborah in the book?

- Have you ever written a poem that explores your feelings about a time when you were “mad”?

Post-reading Discussion Questions:

- In *Part Three “Immortality”*, Rebecca Skloot, becomes a significant part of the story. Why do you think the author decided to include herself as a character in the book? What effect did this have on the understanding of the Lacks family?
- After reading this story, what considerations might you take in your future research that you had not thought about before? Explain.
- The Afterward of the book discusses the role of policy and law to address this ethical debate. What policies do you think should be developed? How might these policies affect the advancement of science?
- There are many powerful topics discussed in this book: Racism, medical ethics, poverty, hope, trust, pride, child abuse, disabilities, lack of education, medical advancements. Pick two or three that interest you the most and discuss how Rebecca Skloot explored them.

Additional reading, discussion questions, and interviews can be found at the following sites:

<http://booklust-lisa.blogspot.com/2010/07/discussion-questions-for-immortal-life.html>

<http://www.theroot.com/views/root-interview-rebecca-skloot>

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

http://www.aarp.org/personal-growth/transitions/info-03-2010/A_Close_Knit_Family1.2.html

http://baltimorereview.org/index.php?option=com_content&task=view&id=18&Itemid=30

Additional questions can also be found at the end of the text on pages 379-381. In particular, consider questions #10 and #11.