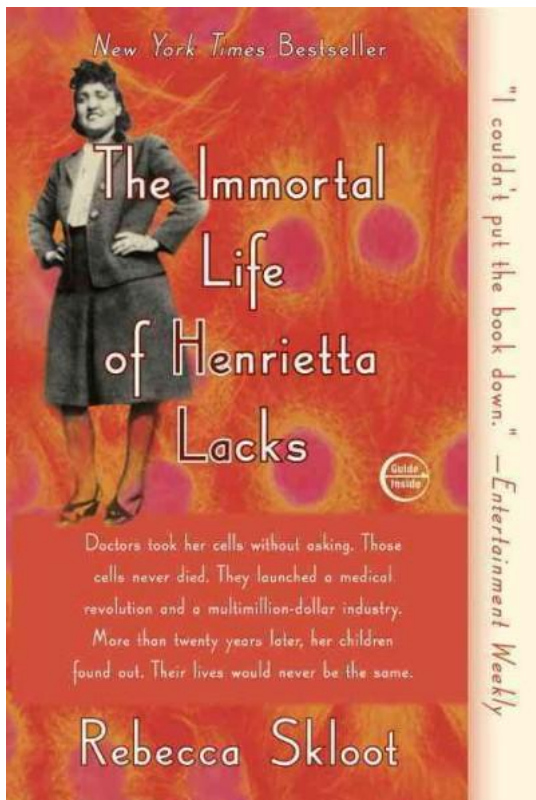


Ann Arbor District Library: Book Club to Go Discussion Guide

<http://www.aadl.org/catalog/record/1400241>

About the Book



Her name was Henrietta Lacks, but scientists know her as HeLa. She was a poor Southern tobacco farmer who worked the same land as her slave ancestors, yet her cells—taken without her knowledge—became one of the most important tools in medicine. The first “immortal” human cells grown in culture, they are still alive today, though she has been dead for more than sixty years. If you could pile all HeLa cells ever grown onto a scale, they’d weigh more than 50 million metric tons—as much as a hundred Empire State Buildings. HeLa cells were vital for developing the polio vaccine; uncovered secrets of cancer, viruses, and the atom bomb’s effects; helped lead to important advances like in vitro fertilization, cloning, and gene mapping; and have been bought and sold by the billions.

Now Rebecca Skloot takes us on an extraordinary journey, from the “colored” ward of Johns Hopkins Hospital in the 1950s to stark white laboratories with freezers full of HeLa cells; from Henrietta’s small, dying hometown of Clover, Virginia—a land of wooden slave quarters, faith healings, and voodoo—to East Baltimore today, where her children and grandchildren live and struggle with the legacy of her cells.

Henrietta’s family did not learn of her “immortality” until more than twenty years after her death, when scientists investigating HeLa began using her husband and children in research without informed consent. And though the cells had launched a multimillion-dollar industry that sells human biological materials, her

family never saw any of the profits. As Rebecca Skloot so brilliantly shows, the story of the Lacks family—past and present—is inextricably connected to the dark history of experimentation on African Americans, the birth of bioethics, and the legal battles over whether we control the stuff we are made of.

Over the decade it took to uncover this story, Rebecca became enmeshed in the lives of the Lacks family—especially Henrietta’s daughter Deborah, who was devastated to learn about her mother’s cells. She was consumed with questions: Had scientists cloned her mother? Did it hurt her when researchers infected her cells with viruses and shot them into space? What happened to her sister, Elsie, who died in a mental institution at the age of fifteen? And if her mother was so important to medicine, why couldn’t her children afford health insurance?

Intimate in feeling, astonishing in scope, and impossible to put down, *The Immortal Life of Henrietta Lacks* captures the beauty and drama of scientific discovery, as well as its human consequences.

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 coeditor 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* bestseller. It was chosen as a best book of 2010 by more than sixty media outlets, including *Entertainment Weekly*, *People*, and the *New York Times*. It is being translated into more than twenty-five 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.

Awards

In 2010, *The Immortal Life of Henrietta Lacks* won the *Chicago Tribune* Heartland Prize for Nonfiction, the Wellcome Trust Book Prize (<http://www.wellcomebookprize.org/>), and the American Association for the Advancement of Science's Award for Excellence in Scientific Writing (<http://www.aaas.org/aboutaaas/awards/>).

Reviews

Booklist Reviews *Starred Review*

The "first immortal human cells," code-named HeLa, have flourished by the trillions in labs all around the world for more than five decades, making possible the polio vaccine, chemotherapy, and many more crucial discoveries. But where did the HeLa cells come from? Science journalist Skloot spent 10 years arduously researching the complex, tragic, and profoundly revealing story of Henrietta Lacks, a 31-year-old African American mother of five who came to Johns Hopkins with cervical cancer in 1951, and from whom tumor samples were taken without her knowledge or that of her family. Henrietta died a cruel death and was all but forgotten, while her miraculous cells live on, "growing with mythological intensity." Skloot travels to tiny Clover, Virginia; learns that Henrietta's family tree embraces black and white branches; becomes close to Henrietta's daughter, Deborah; and discovers that although the HeLa cells have improved countless lives, they have also engendered a legacy of pain, a litany of injustices, and a constellation of mysteries. Writing with a novelist's artistry, a biologist's expertise, and the zeal of an investigative reporter, Skloot tells a truly astonishing story of racism and poverty, science and conscience, spirituality and family driven by a galvanizing inquiry into the sanctity of the body and the very nature of the life force.

Library Journal *Starred Review*

This distinctive work skillfully puts a human face on the bioethical questions surrounding the HeLa cell line. Henrietta Lacks, an African American mother of five, was undergoing treatment for cancer at Johns Hopkins University in 1951 when tissue samples were removed without her knowledge or permission and used to create HeLa, the first "immortal" cell line. HeLa has been sold around the world and used in countless medical research applications, including the development of the polio vaccine. Science writer Skloot, who worked on this book for ten years, entwines Lacks's biography, the development of the HeLa cell line, and her own story of building a relationship with Lacks's children. Full of dialog and vivid detail, this reads like a novel, but the science behind the story is

also deftly handled. VERDICT While there are other titles on this controversy (e.g., Michael Gold's *A Conspiracy of Cells: One Woman's Immortal Legacy—and the Medical Scandal It Caused*), this is the most compelling account for general readers, especially those interested in questions of medical research ethics. Highly recommended.

Kirkus Reviews *Starred Review*

A dense, absorbing investigation into the medical community's exploitation of a dying woman and her family's struggle to salvage truth and dignity decades later. In a well-paced, vibrant narrative, Popular Science contributor and Culture Dish blogger Skloot (Creative Writing/Univ. of Memphis) demonstrates that for every human cell put under a microscope, a complex life story is inexorably attached, to which doctors, researchers and laboratories have often been woefully insensitive and unaccountable. In 1951, Henrietta Lacks, an African-American mother of five, was diagnosed with what proved to be a fatal form of cervical cancer. At Johns Hopkins, the doctors harvested cells from her cervix without her permission and distributed them to labs around the globe, where they were multiplied and used for a diverse array of treatments. Known as HeLa cells, they became one of the world's most ubiquitous sources for medical research of everything from hormones, steroids and vitamins to gene mapping, in vitro fertilization, even the polio vaccine—all without the knowledge, must less consent, of the Lacks family. Skloot spent a decade interviewing every relative of Lacks she could find, excavating difficult memories and long-simmering outrage that had lay dormant since their loved one's sorrowful demise. Equal parts intimate biography and brutal clinical reportage, Skloot's graceful narrative adeptly navigates the wrenching Lack family recollections and the sobering, overarching realities of poverty and pre-civil-rights racism. The author's style is matched by a methodical scientific rigor and manifest expertise in the field. Skloot's meticulous, riveting account strikes a humanistic balance between sociological history, venerable portraiture and Petri dish politics. Tie-in with multicity author lecture schedule.

Publishers Weekly *Starred Review*

Science journalist Skloot makes a remarkable debut with this multilayered story about "faith, science, journalism, and grace." It is also a tale of medical wonders and medical arrogance, racism, poverty and the bond that grows, sometimes painfully, between two very different women—Skloot and Deborah Lacks—sharing an obsession to learn about Deborah's mother, Henrietta, and her magical, immortal cells. Henrietta Lacks was a 31-year-old black mother of five in Baltimore when she died of cervical cancer in 1951. Without her knowledge,

doctors treating her at Johns Hopkins took tissue samples from her cervix for research. They spawned the first viable, indeed miraculously productive, cell line—known as HeLa. These cells have aided in medical discoveries from the polio vaccine to AIDS treatments. What Skloot so poignantly portrays is the devastating impact Henrietta's death and the eventual importance of her cells had on her husband and children. Skloot's portraits of Deborah, her father and brothers are so vibrant and immediate they recall Adrian Nicole LeBlanc's *Random Family*. Writing in plain, clear prose, Skloot avoids melodrama and makes no judgments. Letting people and events speak for themselves, Skloot tells a rich, resonant tale of modern science, the wonders it can perform and how easily it can exploit society's most vulnerable people.

Discussion Questions Source: <http://www.randomhouse.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, recreate 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 non-native 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 sentence. 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 give *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 Lacks' response to and interpretation of the scientific information they receive about HeLa? How does Skloot's attitude towards 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? 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?

Multimedia

'Immortal' Cells of Henrietta Lacks Live on in Labs (Radio Broadcast)

<http://www.npr.org/2010/12/13/132030076/henrietta-lacks-immortal-cells-live-on-in-labs>

A discussion of the book and its subject with the author on NPR's *Talk of the Nation*.

A Conversation with Rebecca Skloot (Video Clip)

<http://www.youtube.com/watch?v=4AuOWSOzdcA>

WKNO's Pierre Kimsey interviews Rebecca Skloot, science journalist and contributing editor at Popular Science magazine who makes her home in Memphis. *The Immortal Life of Henrietta Lacks*, her debut book, uncovers the heretofore unknown story of the woman whose cancerous cells were cultivated, without her family's consent or knowledge, into the first "immortal" human cell culture and helped provide some of the major advances in 20th century medicine.

Further Reading

Merchants of Doubt: How a Handful of Scientists Obscured the Truth on Issues from Tobacco Smoke to Global Warming by Naomi Oreskes and Erik M. Conway

<http://www.aadl.org/catalog/record/1364309>

(Call number: 174.95 Or)

Science historians Naomi Oreskes and Erik Conway explore the role that a group of politically and financially motivated scientists played in swaying the public's perceived risk of specific health and environmental issues. Citing such scientists as Robert Jastrow, Frederick Seitz, and S. Fred Singer--all connected politically--the authors reveal how their systematic distortion of information perpetrated flawed public comprehension of acid rain, tobacco smoke, DDT, the depletion of the ozone layer, global warming, and the Strategic Defense Initiative.

Better for All the World: The Secret History of Forced Sterilization and America's Quest for Racial Purity by Harry Bruinius

<http://www.aadl.org/catalog/record/1262094>

(Call number: 363.97 Br)

A timely and gripping history of the controversial eugenics movement in America--and the scientists, social reformers and progressives who supported it.

In *Better for All the World*, Harry Bruinius charts the little known history of eugenics in America—a movement that began in the early twentieth century and resulted in the forced sterilization of more than 65,000 people. Bruinius tells the stories of Emma and Carrie Buck, two women trapped in poverty who became the test case in the 1927 supreme court decision allowing forced sterilization for those deemed unfit to procreate. From the reformers who turned local charities into government-run welfare systems promoting social and moral purity, to the influence the American policies had on Nazi Germany’s development of “racial hygiene,” Bruinius masterfully exposes the players and legislation behind one of America’s darkest secrets.

Charity Girl by Michael Lowenthal

<http://www.aadl.org/catalog/record/1277850>

(Call number: Fiction Lowenthal)

Approximately 30,000 American women suspected of carrying venereal diseases were interned during World War I. This account fictionalizes the experience of one of them, Frieda Mintz, a teenager working in the lingerie department of the Jordan Marsh department store in Boston. A fling with an Army private from a high-profile Boston family leaves her with a sexually-transmitted disease, and she's quickly taken to a detention camp when she's found out.

Author's official website

<http://rebeccaskloot.com/>

Information, appearances, and news about the author.

Read-Alikes

****Book Club To Go! Fierce Radiance*** by Lauren Belfer

<http://www.aadl.org/catalog/record/1362576>

(Call number: Fiction Belfer)

In the anxious days after Pearl Harbor, talented "Life" magazine reporter Clara Shipley finds herself on top of one of the nation's most important stories--the race to discover penicillin at the Rockefeller Institute. When a researcher at the institute dies under suspicious circumstances, the stakes become starkly clear: a murder has been committed to obtain these lucrative new drugs. With lives and a new love hanging in the balance, Claire will put herself at the center of danger to find a killer--no matter what price she may have to pay.

The Hemingses of Monticello: An American Family by Annette Gordon-Reed

<http://www.aadl.org/catalog/record/1317299>

(Call number: 929.2 He)

An in-depth examination of the relationship between Thomas Jefferson and his slave Sally Hemings, along with the rest of the Hemings family. Jefferson allegedly fathered a number of Sally Hemings's children, and this is discussed at length. The lives of those children are discussed, as well as Sally Hemings's siblings, who were also related to Jefferson's wife. Important events serve as the backdrop for the family, including Revolutionary America, Philadelphia in the 1790s, and the revolution in Paris, as well as life at the plantation Monticello. Information about the nature of the slaves' lives is included as well.

Strength in What Remains by Tracy Kidder

<http://www.aadl.org/catalog/record/1339462>

(Call number: 305.896 Ki)

Strength in What Remains is a biography by Tracy Kidder of Deogratias, known as Deo. Deo was still a young man when he fled his home in the African nation of Burundi in 1993 after civil war broke out. Deo traveled through Rwanda, surviving the genocide taking place there, and eventually wound up in New York City, struggling to survive on very meager wages. Through the help of strangers who reached out to him, Deo was able to attend Columbia University and get his medical degree along with his American citizenship. Despite the fact that Deo would never need to return to Burundi, he still travels there regularly to work on creating a public health system and open medical clinics. Deo was able to turn the horrors of his young life into something positive for many people in his country of Burundi, and continues to make the country a better place with his strength.



Ann Arbor District Library