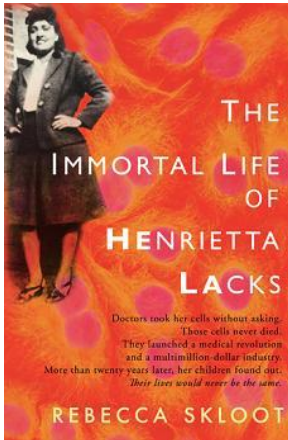


The Immortal Life of Henrietta Lacks

By Rebecca Skloot



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ABOUT THIS 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.

Yet Henrietta Lacks remains virtually unknown, buried in an unmarked grave.

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.

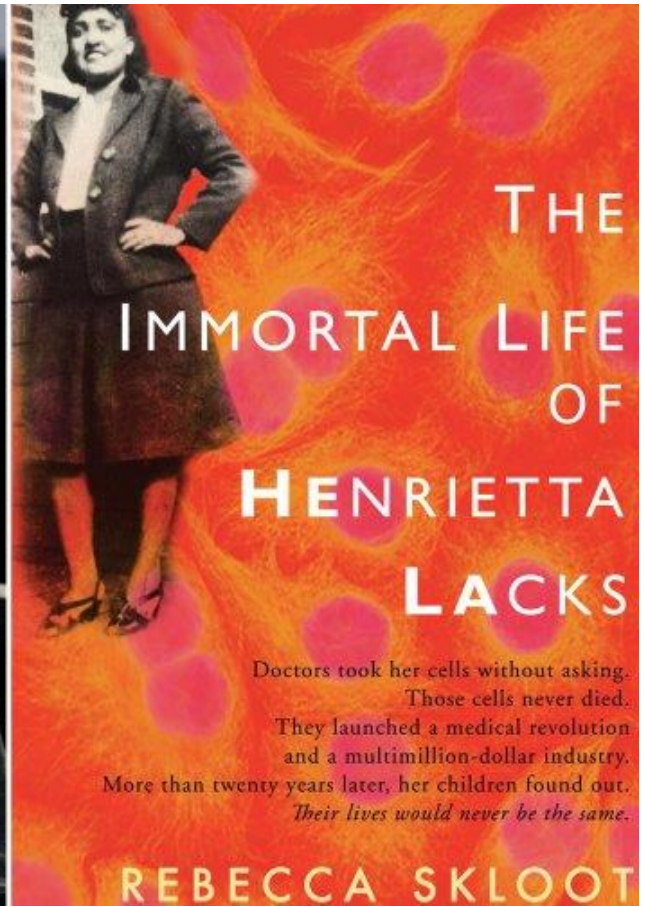
QUESTIONS FOR DISCUSSION

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?

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Rebecca Skloot: How I Write

The author of *The Immortal Life of Henrietta Lacks*, which has been on the New York Times paperback bestseller list for more than 100 weeks now, on how she found the story that inspired the megahit, and her meticulous research and interview process.

How did you first come across the story of Henrietta Lacks? Did you immediately see a book in it, feel a “click” moment?

I first learned about Henrietta Lacks and her amazing cells when I was 16 in a basic biology class at the local community college (a class I was taking because I'd failed biology at the local high school and I was trying to make up the credits to graduate). At that point I was planning to be a veterinarian, so I didn't immediately think, Ah! I'm going to write a book about Henrietta! So a “click” definitely happened in that moment that changed my life, but it wasn't a moment that made me realize I wanted to be a writer, and that I wanted to write about Henrietta. That didn't happen for another decade. You can read the story behind that [here](#).

It took you about a decade to research and write [The Immortal Life of Henrietta Lacks](#). A long time for any project (but certainly worth the wait). Can you describe that decade, walking us through the process?

Ha, no chance! To break that down into any coherent timeline would require a several-thousand word answer to your question. Between researching, writing, and publishing *The Immortal Life*, then doing endless book touring since it came out, I've been working on the book for 13 years and counting.

For starters, it took me more than a year and a half just to convince the Lacks family to talk with me for the first time. They didn't trust me, or any other writer—all for good reasons, which I'd eventually find out. During the decade that led up to the book's publication, while researching and writing it, I also had to build a freelance career publishing in magazines and newspapers (so I could pay my bills and fund the research for my book—with the help of a lot of credit cards and student loans—while also building my bio enough so a publishing house would someday want to publish my book). I got a big stack of rejection letters from editors, then and once I got a book contract, I fought some pretty big publishing battles (including one in which an editor insisted that I had to take the Lacks family out of the book). By the time the book was finally published, I was on my fifth editor and my third publishing house. Along the way, I also got married, got divorced, finished grad school, taught at three different universities, moved eight times ... I'll stop there.

Describe your morning routine.

My morning routine varies depending on where I am in my writing process. Right now I'm in the information-gathering stage of things, which means I wake up around 9 a.m. and read the morning news (via Twitter and Facebook and various newspaper sites) on my phone in bed. When I'm done, before I take a single step, I grab my pedometer off my bedside table and attach it to my clothes, as do several other writers I know, including [A.J. Jacobs](#). We have a step-racing competition going through an online site so we can see who takes the most steps per day and per week (as of this moment, I'm winning, but I have an unfair advantage because A.J. lost his for a few days this week).

Once I'm out of bed, I let dogs out, let dogs in (sometimes more than once because one of them is very indecisive). I make myself a latte, then I go to my office.

When I'm on deadline or trying to get some serious writing done, all of that changes (except the pedometer): I wake up at 5 a.m. (which sucks—I'm not a morning person), and stagger to a nearby coffee shop where I bury myself in my laptop with headphones on to write as long as I can stand it (usually about four hours). Then I go to a different coffee shop where I eat and write as much as I can before I go home for the day to do busywork like email and whatnot because by that point I'm useless.

What is a distinctive habit or affectation of yours?

I do everything fast (I talk fast, type fast, move fast)—I also gesture a lot. Those things don't tend to go well together, which means I'm clumsy. Anyone who knows me well has stories of me spilling things on them, running into things, sending glasses full of red wine flying across rooms, and just being generally and unintentionally slapstick.

What is your favorite item of clothing?

I'm very sentimental about my jewelry: I've been wearing the same ring on my left ring finger for 26 years. I got it with one of my best friends when we were 14, and I never take it off. My ears are pierced eight times, and each of those earrings has an old story behind it. On my right wrist is a bracelet I never take off from a former student; my necklace, which also never comes off, another old and dear story.

Your father ([Floyd Skloot](#)) is an excellent writer, as well (and judging by his Facebook posts, he is also the captain of your fan club). What was it like to grow up with a writer father, and how did it influence/inspire your own work?

Growing up with a writer for a father influenced me and my work in many ways. My father really taught me how to see the world through a writer's eyes, especially when it came to character development. For most of my childhood he was working on his first novel, [Pilgrim's Harbor](#), about a man named Dewey Howser, who owned a hotel. When we went out to dinner, we would make reservations as the Howsers, and we'd spend our time making up stories for different people in the restaurant. It was a character development game—we'd talk in accents, invent detailed backstories, even dialogue for what they were saying during dinner. For me and my brother, this was just a fun game, but looking back I now understand that those "games" were my father's way of trying to work on his book, squeezing it in while raising kids, working a full-time job. *Pilgrim's Harbor* was filled with minor characters coming and going from the hotel—many of them were ones we developed while playing that family game. My writing has always been very character driven, and I don't think that's a coincidence.

Do you have a writer friend who helps and inspires you?

I have several of them, but the one who helps and inspires me most is [Mike Rosenwald](#), an incredible narrative writer and *Washington Post* reporter. We met in grad school 15 years ago and have been close friends ever since. We read each other's work, bounce ideas around, brainstorm about reporting and whatever else. We also push each other with some serious tough love when needed. Someday I want to count the number of emails/texts/IMs we send each other each week. We're both compulsive email savers, so I'd put money on the fact that our email exchange archives exceeded a million messages long ago.

Describe your routine when conceiving of a book, mapping it out and researching, before the writing begins.

Structure is very important to me. I have to know where I'm going before I can write in earnest (though I constantly draft scenes that will go in the book). I used index cards and a very large wall for my book—I've written in detail about that process [here](#), where you can see photos of those index cards.

Is there anything distinctive or unusual about your work space? Besides the obvious, what do you keep on your desk? What is the view from your favorite work space?

This year I turned the attic of my old house (more than 100 years old) into my office. I painted it three different shades of purple (my favorite color—I've painted every bedroom and office of my life in various and extreme shades of purple). It has a peaked ceiling with dark wood support beams, and the walls slope with the roof. A friend of mine designed special angular bookshelves to fit along the roofline, since there are no flat walls for traditional shelves.

As for the view (and the natural light): I put in several big roof window skylights, so I can stare from my desk at nothing but trees and sky, because being in a remote place (or feeling like I'm in a remote place) is essential for my writing. While working on *The Immortal Life*, I lived in very small apartments, mostly in New York City, and couldn't write at home. I would escape to a friend's farmhouse in rural West Virginia, where I could stare out at lush rolling hills for miles. My stepmother once painted that view for me on a big canvas, which now hangs on one wall of my office, so I can stare out into those hills without leaving Chicago, where I live.

My office is full of little things with hidden stories. Like the old twisted metal sign that simply says "DOGS," which hangs on the exposed brick of my chimney. I tore that sign off a junkyard gate in Manhattan, a trophy and a reminder, after

winning a yearlong battle to get the city to deal with faulty laws and a pack of junkyard dogs that roamed loose not far from Penn Station and had nearly killed my dog, Bonny (which [I wrote about here](#)).

What's probably most notable about my workspace is that I write while walking at a treadmill desk. You can read all about my tread-desk set-up and see photos of it [here](#). (This is where that pedometer racing I mentioned earlier comes in—several other writers and I who work at tread desks sync our pedometers online and compete to see who walks farthest each day, week, etc). My dog Clarence and cat, Phineas, often hang out together in swivel chairs by my bookshelves while my dog Rhoda sleeps under my desk, but they all rotate positions throughout the day. Funny things happen when the animals get curious about the tread desk. Especially the cat.

What is guaranteed to make you laugh?

Animal videos on YouTube.

What is guaranteed to make you cry?

Animal videos on YouTube.

Do you have any superstitions?

Do you have a lot of time?

If you could bring back to life one deceased person, who would it be and why?

Deborah Lacks. So she could see how the world has responded to *The Immortal Life of Henrietta Lacks*. So she could go on tour to talk with readers about her mother, HeLa cells, and the book, which she always wanted to do. So she could finally fulfill her lifelong dream of meeting Oprah and seeing her turn *The Immortal Life of Henrietta Lacks* into a movie. And because I miss her.

What is your favorite snack?

My boyfriend's homemade pizza, cold in the morning.

What phrase do you over-use?

"Definitely" ... it's a tick one of my best friends and I picked up after watching *Rain Man* a few too many times.

Was there a specific moment when you felt you had "made it" as an author?

In chronological order: When the story of Henrietta Lacks was "ripped" for an episode of *Law and Order*. When my book was an answer to a Jeopardy question. When *The Immortal Life of Henrietta Lacks* showed up in the movie *Think Like a Man* as a tool for successfully picking up women in bookstores.

Tell us a funny story related to a book tour or book event.

Oh wow, there are so many! A few highlights: A college student trying to kiss me at the book-signing table with hundreds of people watching in line behind him (not recommended). Being accosted by a drunken professor and pushed on stage (which broke the heel off my boot) in front of thousands of students.

Also I have a very long list of surprising things people have asked me to sign at book events (which I love). A few notable entries: A petri dish, a dog's collar, many shoes and jackets, numerous cheeks and arms, a parking ticket, many vials of HeLa cells, a license plate (is that legal?), a cellphone battery, and a color photo of what one woman described as her "hairy ovarian cyst."

What would you like carved onto your tombstone?

"I said I wanted to be cremated!"

What is your next book project? Have you found a new story that resonates with you yet?

My next book project goes back to my lifelong interests in animals, veterinary medicine, science, and ethics. I'm still in the early stages of working on it, so it's hard for me to talk about in too much detail (I'm not one of those writers who doesn't talk about work in progress, I just haven't figured out how to talk about this one yet, since it's still in its early stages, and it's a complicated one). You can read a description of it [online here](#).