PRAISE FOR REBECCA SKLOOT'S

THE IMMORTAL LIFE OF HENRIETTA LACKS

Winner of 2010 Chicago Tribune Heartland Prize for Nonfiction
Winner of 2010 Wellcome Trust Book Prize
New York Times Notable Book
New Yorker Reviewers' Favorite
Entertainment Weekly Best Book of the Year
O, The Oprah Magazine Best Book of the Year
National Public Radio Best of the Bestsellers
Financial Times Nonfiction Favorite
Los Angeles Times Critics' Pick
New York magazine Top Ten Book of the Year
Discover magazine 2010 Must-Read
Independent (U.K.) Best Book of the Year
Publishers Weekly Best Book of the Year
Library Journal Best Book of the Year
Kirkus Reviews Best Book of the Year
Times (U.K.) Best Book of the Year
U.S. News & World Report Talk-Worthy Title
Booklist Best Book of the Year
Globe and Mail Best Book of the Year

"I could not put the book down... The story of modern medicine and bioethics—and, indeed, race relations—is refracted beautifully, and movingly."
—ENTERTAINMENT WEEKLY

"Science writing is often just about 'the facts.' Skloot's book, her first, is far deeper, braver, and more wonderful."
—NEW YORK TIMES BOOK REVIEW

"The Immortal Life of Henrietta Lacks is a triumph of science writing... one of the best nonfiction books I have ever read."
—WIRZED.COM

"A deftly crafted investigation of a social wrong committed by the medical establishment, as well as the scientific and medical miracles to which it led."
—WASHINGTON POST

"Riveting... a tour-de-force debut."
—CHICAGO SUN-TIMES

"A real-life detective story, The Immortal Life of Henrietta Lacks probes deeply into racial and ethical issues in medicine... The emotional impact of Skloot's tale is intensified by its skillfully orchestrated counterpoint between two worlds."
—NATURE

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This is a work of nonfiction. No names have been changed, no characters invented, no events fabricated. While writing this book, I conducted more than a thousand hours of interviews with family and friends of Henrietta Lacks, as well as with lawyers, ethicists, scientists, and journalists who’ve written about the Lacks family. I also relied on extensive archival photos and documents, scientific and historical research, and the personal journals of Henrietta’s daughter, Deborah Lacks.

I’ve done my best to capture the language with which each person spoke and wrote: dialogue appears in native dialects; passages from diaries and other personal writings are quoted exactly as written. As one of Henrietta’s relatives said to me, “If you pretty up how people spoke and change the things they said, that’s dishonest. It’s taking away their lives, their experiences, and their selves.” In many places I’ve adopted the words interviewees used to describe their worlds and experiences. In doing so, I’ve used the language of their times and backgrounds, including words such as colored. Members of the Lacks family often referred to Johns Hopkins as “John Hopkin,” and I’ve
kept their usage when they’re speaking. Anything written in the first person in Deborah Lacks’s voice is a quote of her speaking, edited for length and occasionally clarity.

Since Henrietta Lacks died decades before I began writing this book, I relied on interviews, legal documents, and her medical records to re-create scenes from her life. In those scenes, dialogue is either deduced from the written record or quoted verbatim as it was recounted to me in an interview. Whenever possible I conducted multiple interviews with multiple sources to ensure accuracy. The extract from Henrietta’s medical record in chapter 1 is a summary of many disparate notations.

The word HeLa, used to refer to the cells grown from Henrietta Lacks’s cervix, occurs throughout the book. It is pronounced bee-lab.

About chronology: Dates for scientific research refer to when the research was conducted, not when it was published. In some cases those dates are approximate because there is no record of exact start dates. Also, because I move back and forth between multiple stories, and scientific discoveries occur over many years, there are places in the book where, for the sake of clarity, I describe scientific discoveries sequentially, even though they took place during the same general period of time.

The history of Henrietta Lacks and the HeLa cells raises important issues regarding science, ethics, race, and class; I’ve done my best to present them clearly within the narrative of the Lacks story, and I’ve included an afterword addressing the current legal and ethical debate surrounding tissue ownership and research. There is much more to say on all the issues, but that is beyond the scope of this book, so I will leave it for scholars and experts in the field to address. I hope readers will forgive any omissions.
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.

—Elie Wiesel
from The Nazi Doctors and the Nuremberg Code

There’s a photo on my wall of a woman I’ve never met, its left corner torn and patched together with tape. She looks straight into the camera and smiles, hands on hips, dress suit neatly pressed, lips painted deep red. It’s the late 1940s and she hasn’t yet reached the age of thirty. Her light brown skin is smooth, her eyes still young and playful, oblivious to the tumor growing inside her—a tumor that would leave her five children motherless and change the future of medicine. Beneath the photo, a caption says her name is “Henrietta Lacks, Helen Lane or Helen Larson.”

No one knows who took that picture, but it’s appeared hundreds of times in magazines and science textbooks, on blogs and laboratory walls. She’s usually identified as Helen Lane, but often she has no name at all. She’s simply called HeLa, the code name given to the world’s first immortal human cells—her cells, cut from her cervix just months before she died.

Her real name is Henrietta Lacks.

I’ve spent years staring at that photo, wondering what kind of life she led, what happened to her children, and what she’d think about
cells from her cervix living on forever—bought, sold, packaged, and shipped by the trillions to laboratories around the world. I’ve tried to imagine how she’d feel knowing that her cells went up in the first space missions to see what would happen to human cells in zero gravity, or that they helped with some of the most important advances in medicine: the polio vaccine, chemotherapy, cloning, gene mapping, in vitro fertilization. I’m pretty sure that she—like most of us—would be shocked to hear that there are trillions more of her cells growing in laboratories now than there ever were in her body.

There’s no way of knowing exactly how many of Henrietta’s cells are alive today. One scientist estimates that if you could pile all HeLa cells ever grown onto a scale, they’d weigh more than 50 million metric tons—an inconceivable number, given that an individual cell weighs almost nothing. Another scientist calculated that if you could lay all HeLa cells ever grown end-to-end, they’d wrap around the Earth at least three times, spanning more than 350 million feet. In her prime, Henrietta herself stood only a bit over five feet tall.

I first learned about HeLa cells and the woman behind them in 1988, thirty-seven years after her death, when I was sixteen and sitting in a community college biology class. My instructor, Donald Defler, a gnomish balding man, paced at the front of the lecture hall and flipped on an overhead projector. He pointed to two diagrams that appeared on the wall behind him. They were schematics of the cell reproduction cycle, but to me they just looked like a neon-colored mess of arrows, squares, and circles with words I didn’t understand, like “MPF Triggering a Chain Reaction of Protein Activations.”

I was a kid who’d failed freshman year at the regular public high school because she never showed up. I’d transferred to an alternative school that offered dream studies instead of biology, so I was taking Defler’s class for high-school credit, which meant that I was sitting in a college lecture hall at sixteen with words like mitosis and kinase inhibitors flying around. I was completely lost.

“Do we have to memorize everything on those diagrams?” one student yelled.

Yes, Defler said, we had to memorize the diagrams, and yes, they’d be on the test, but that didn’t matter right then. What he wanted us to understand was that cells are amazing things: There are about one hundred trillion of them in our bodies, each so small that several thousand could fit on the period at the end of this sentence. They make up all our tissues—muscle, bone, blood—which in turn make up our organs.

Under the microscope, a cell looks a lot like a fried egg: It has a white (the cytoplasm) that’s full of water and proteins to keep it fed, and a yolk (the nucleus) that holds all the genetic information that makes you you. The cytoplasm buzzes like a New York City street. It’s crammed full of molecules and vessels endlessly shuttling enzymes and sugars from one part of the cell to another, pumping water, nutrients, and oxygen in and out of the cell. All the while, little cytoplasmic factories work 24/7, cranking out sugars, fats, proteins, and energy to keep the whole thing running and feed the nucleus—the brains of the operation. Inside every nucleus within each cell in your body, there’s an identical copy of your entire genome. That genome tells cells when to grow and divide and makes sure they do their jobs, whether that’s controlling your heartbeat or helping your brain understand the words on this page.

Defler paced the front of the classroom telling us how mitosis—the process of cell division—makes it possible for embryos to grow into babies, and for our bodies to create new cells for healing wounds or replenishing blood we’ve lost. It was beautiful, he said, like a perfectly choreographed dance.

All it takes is one small mistake anywhere in the division process for cells to start growing out of control, he told us. Just one enzyme misfiring, just one wrong protein activation, and you could have cancer. Mitosis goes haywire, which is how it spreads.

“We learned that by studying cancer cells in culture,” Defler said. He grinned and spun to face the board, where he wrote two words in enormous print: HENRIETTA LACKS.

Henrietta died in 1951 from a vicious case of cervical cancer, he
told us. But before she died, a surgeon took samples of her tumor and put them in a petri dish. Scientists had been trying to keep human cells alive in culture for decades, but they all eventually died. Henrietta’s were different: they reproduced an entire generation every twenty-four hours, and they never stopped. They became the first immortal human cells ever grown in a laboratory.

“Henrietta’s cells have now been living outside her body far longer than they ever lived inside it,” Defler said. If we went to almost any cell culture lab in the world and opened its freezers, he told us, we’d probably find millions—if not billions—of Henrietta’s cells in small vials on ice.

Her cells were part of research into the genes that cause cancer and those that suppress it; they helped develop drugs for treating herpes, leukemia, influenza, hemophilia, and Parkinson’s disease; and they’ve been used to study lactose digestion, sexually transmitted diseases, appendicitis, human longevity, mosquito mating, and the negative cellular effects of working in sewers. Their chromosomes and proteins have been studied with such detail and precision that scientists know their every quirk. Like guinea pigs and mice, Henrietta’s cells have become the standard laboratory workhorse.

“HeLa cells were one of the most important things that happened to medicine in the last hundred years,” Defler said.

Then, matter-of-factly, almost as an afterthought, he said, “She was a black woman.” He erased her name in one fast swipe and blew the chalk from his hands. Class was over.

As the other students filed out of the room, I sat thinking, That’s it? That’s all we get? There has to be more to the story.

I followed Defler to his office.

“Where was she from?” I asked. “Did she know how important her cells were? Did she have any children?”

“I wish I could tell you,” he said, “but no one knows anything about her.”

After class, I ran home and threw myself onto my bed with my biology textbook. I looked up “cell culture” in the index, and there she was, a small parenthetical:

In culture, cancer cells can go on dividing indefinitely, if they have a continual supply of nutrients, and thus are said to be “immortal.” A striking example is a cell line that has been reproducing in culture since 1951. (Cells of this line are called HeLa cells because their original source was a tumor removed from a woman named Henrietta Lacks.)

That was it. I looked up HeLa in my parents’ encyclopedia, then my dictionary: No Henrietta.

As I graduated from high school and worked my way through college toward a biology degree, HeLa cells were omnipresent. I heard about them in histology, neurology, pathology; I used them in experiments on how neighboring cells communicate. But after Mr. Defler, no one mentioned Henrietta.

When I got my first computer in the mid-nineties and started using the Internet, I searched for information about her, but found only confused snippets: most sites said her name was Helen Lane; some said she died in the thirties; others said the forties, fifties, or even sixties. Some said ovarian cancer killed her, others said breast or cervical cancer.

Eventually I tracked down a few magazine articles about her from the seventies. Ebony quoted Henrietta’s husband saying, “All I remember is that she had this disease, and right after she died they called me in the office wanting to get my permission to take a sample of some kind. I decided not to let them.” Jet said the family was angry—angry that Henrietta’s cells were being sold for twenty-five dollars a vial, and angry that articles had been published about the cells without their knowledge. It said, “Pounding in the back of their heads was a gnawing feeling that science and the press had taken advantage of them.”

The articles all ran photos of Henrietta’s family: her oldest son sitting at his dining room table in Baltimore, looking at a genetics
textbook. Her middle son in military uniform, smiling and holding a baby. But one picture stood out more than any other: in it, Henrietta’s daughter, Deborah Lack, is surrounded by family, everyone smiling, arms around each other, eyes bright and excited. Except Deborah. She stands in the foreground looking alone, almost as if someone passed her into the photo after the fact. She’s twenty-six years old and beautiful, with short brown hair and catlike eyes. But those eyes glare at the camera, hard and serious. The caption said the family had found out just a few months earlier that Henrietta’s cells were still alive, yet at that point she’d been dead for twenty-five years.

All of the stories mentioned that scientists had begun doing research on Henrietta’s children, but the Lackses didn’t seem to know what that research was for. They said they were being tested to see if they had the cancer that killed Henrietta, but according to the reporters, scientists were studying the Lack family to learn more about Henrietta’s cells. The stories quoted her son Lawrence, who wanted to know if the immortality of his mother’s cells meant that he might live forever too. But one member of the family remained voiceless: Henrietta’s daughter, Deborah.

As I worked my way through graduate school studying writing, I became fixated on the idea of someday telling Henrietta’s story. At one point I even called directory assistance in Baltimore looking for Henrietta’s husband, David Lack, but he wasn’t listed. I had the idea that I’d write a book that was a biography of both the cells and the woman they came from—one’s daughter, wife, and mother.

I couldn’t have imagined it then, but that phone call would mark the beginning of a decade-long adventure through scientific laboratories, hospitals, and mental institutions, with a cast of characters that would include Nobel laureates, grocery store clerks, convicted felons, and a professional con artist. While trying to make sense of the history of cell culture and the complicated ethical debate surrounding the use of human tissues in research, I’d be accused of conspiracy and slammed into a wall both physically and metaphorically, and I’d eventually find myself on the receiving end of something that looked a lot like an exorcism. I did eventually meet Deborah, who would turn out to be one of the strongest and most resilient women I’d ever known. We’d form a deep personal bond, and slowly, without realizing it, I’d become a character in her story, and she in mine.

Deborah and I came from very different cultures: I grew up white and agnostic in the Pacific Northwest, my roots half New York Jew and half Midwestern Protestant; Deborah was a deeply religious black Christian from the South. I tended to leave the room when religion came up in conversation because it made me uncomfortable; Deborah’s family tended toward preaching, faith healings, and sometimes voodoo. She grew up in a black neighborhood that was one of the poorest and most dangerous in the country; I grew up in a safe, quiet middle-class neighborhood in a predominantly white city and went to high school with a total of two black students. I was a science journalist who referred to all things supernatural as “woo-woo stuff”; Deborah believed Henrietta’s spirit lived on in her cells, controlling the life of anyone who crossed its path. Including me.

“How else do you explain why your science teacher knew her real name when everyone else called her Helen Lane?” Deborah would say. “She was trying to get your attention.” This thinking would apply to everything in my life: when I married while writing this book, it was because Henrietta wanted someone to take care of me while I worked. When I divorced, it was because she’d decided he was getting in the way of the book. When an editor who insisted I take the Lack family out of the book was injured in a mysterious accident, Deborah said that’s what happens when you piss Henrietta off.

The Lackses challenged everything I thought I knew about faith, science, journalism, and race. Ultimately, this book is the result. It’s not only the story of HeLa cells and Henrietta Lack, but of Henrietta’s family—particularly Deborah—and their lifelong struggle to make peace with the existence of those cells, and the science that made them possible.
On January 29, 1951, David Lacks sat behind the wheel of his old Buick, watching the rain fall. He was parked under a towering oak tree outside Johns Hopkins Hospital with three of his children—two still in diapers—waiting for their mother, Henrietta. A few minutes earlier she'd jumped out of the car, pulled her jacket over her head, and scurried into the hospital, past the "colored" bathroom, the only one she was allowed to use. In the next building, under an elegant domed copper roof, a ten-and-a-half-foot marble statue of Jesus stood, arms spread wide, holding court over what was once the main entrance of Hopkins. No one in Henrietta's family ever saw a Hopkins doctor without visiting the Jesus statue, laying flowers at his feet, saying a prayer, and rubbing his big toe for good luck. But that day Henrietta didn't stop.

She went straight to the waiting room of the gynecology clinic, a wide-open space, empty but for rows of long straight-backed benches that looked like church pews.

"I got a knot on my womb," she told the receptionist. "The doctor need to have a look."
For more than a year Henrietta had been telling her closest girl-
friends something didn’t feel right. One night after dinner, she sat on
her bed with her cousins Margaret and Sadie and told them, “I got a
knot inside me.”

“A what?” Sadie asked.

“A knot,” she said. “It hurt somethin’ awful — when that man want
to get with me, Sweet Jesus aren’t them but some pains.”

When sex first started hurting, she thought it had something to do
with baby Deborah, who she’d just given birth to a few weeks earlier,
or the bad blood David sometimes brought home after nights with
other women — the kind doctors treated with shots of penicillin and
heavy metals.

Henrietta grabbed her cousins’ hands one at a time and guided
them to her belly, just as she’d done when Deborah started kicking.

“You feel anything?”

The cousins pressed their fingers into her stomach again and again.

“I don’t know,” Sadie said. “Maybe you’re pregnant outside your
womb — you know that can happen.”

“I’m no kind of pregnant,” Henrietta said. “It’s a knot.”

“Hennie, you gotta check that out. What if it’s somethin’ bad?”

But Henrietta didn’t go to the doctor, and the cousins didn’t tell
anyone what she’d said in the bedroom. In those days, people didn’t
talk about things like cancer, but Sadie always figured Henrietta kept
it secret because she was afraid a doctor would take her womb and
make her stop having children.

About a week after telling her cousins she thought something was
wrong, at the age of twenty-nine, Henrietta turned up pregnant with
Joe, her fifth child. Sadie and Margaret told Henrietta that the pain
probably had something to do with a baby after all. But Henrietta still
said no.

“It was there before the baby,” she told them. “It’s somethin’ else.”

They all stopped talking about the knot, and no one told Henri-
etta’s husband anything about it. Then, four and a half months after

baby Joseph was born, Henrietta went to the bathroom and found
blood spotting her underwear when it wasn’t her time of the month.

She filled her bathtub, lowered herself into the warm water, and
spread her legs. With the door closed to her children, husband, and
cousins, Henrietta slid a finger inside herself and rubbed it across her
cervix until she found what she somehow knew she’d find: a hard
lump, deep inside, as though someone had lodged a marble just to the
left of the opening to her womb.

Henrietta climbed out of the bathtub, dried herself off, and
dressed. Then she told her husband, “You better take me to the doc-
tor. I’m bleedin’ and it ain’t my time.”

Her local doctor took one look inside her, saw the lump, and fig-
ured it was a sore from syphilis. But the lump tested negative for
syphilis, so he told Henrietta she’d better go to the Johns Hopkins
gynecology clinic.

Hopkins was one of the top hospitals in the country. It was built
in 1889 as a charity hospital for the sick and poor, and it covered more
than a dozen acres where a cemetery and insane asylum once sat in
East Baltimore. The public wards at Hopkins were filled with pa-
ients, 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
continued 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.

So when the nurse called Henrietta from the waiting room, she led
her through a single door to a colored-only exam room — one in a long
row of rooms divided by clear glass walls that let nurses see from one
to the next. Henrietta undressed, wrapped herself in a starched white
hospital gown, and lay down on a wooden exam table, waiting for
Howard Jones, the gynecologist on duty. Jones was thin and graying,
his deep voice softened by a faint Southern accent. When he walked into the room, Henrietta told him about the lump. Before examining her, he flipped through her chart—a quick sketch of her life, and a litany of untreated conditions:

Sixth or seventh grade education; housewife and mother of five. Breathing difficult since childhood due to recurrent throat infections and deviated septum in patient’s nose. Physician recommended surgical repair. Patient declined. Patient had one toothache for nearly five years; tooth eventually extracted with several others. Only anxiety is oldest daughter who is epileptic and can’t talk. Happy household. Very occasional drinker. Has not traveled. Well nourished, cooperative. Patient was one of ten siblings. One died of car accident, one from rheumatic heart, one was poisoned. Unexplained vaginal bleeding and blood in urine during last two pregnancies; physician recommended sickle cell test. Patient declined. Been with husband since age 15 and has no liking for sexual intercourse. Patient has asymptomatic neurosyphilis but cancelled syphilis treatments, said she felt fine. Two months prior to current visit, after delivery of fifth child, patient had significant blood in urine. Tests showed areas of increased cellular activity in the cervix. Physician recommended diagnostics and referred to specialist for ruling out infection or cancer. Patient canceled appointment. One month prior to current visit, patient tested positive for gonorrhea. Patient recalled to clinic for treatment. No response.

It was no surprise that she 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. She knew about harvesting tobacco and butchering a pig, but she’d never heard the words cervix or biopsy. She didn’t read or write much, and she hadn’t studied science in school. She, like most black patients, only went to Hopkins when she thought she had no choice.

Jones listened as Henrietta told him about the pain, the blood. "She says that she knew there was something wrong with the neck of her womb," he wrote later. "When asked why she knew it, she said that she felt as if there were a lump there. I do not quite know what she means by this, unless she actually palpated this area."

Henrietta lay back on the table, feet pressed hard in stirrups as she stared at the ceiling. And sure enough, Jones found a lump exactly where she’d said he would. He described it as an eroded, hard mass about the size of a nickel. If her cervix was a clock’s face, the lump was at four o’clock. He’d seen easily a thousand cervical cancer lesions, but never anything like this: shiny and purple (like “grape Jello,” he wrote later), and so delicate it bled at the slightest touch. Jones cut a small sample and sent it to the pathology lab down the hall for diagnosis. Then he told Henrietta to go home.

Soon after, Jones sat down and dictated notes about Henrietta and her diagnosis: "Her history is interesting in that she had a term delivery here at this hospital, September 19, 1950," he said. "No note is made in the history at that time, or at the six weeks' return visit that there is any abnormality of the cervix."

Yet here she was, three months later, with a full-fledged tumor. Either her doctors had missed it during her last exams—which seemed impossible—or it had grown at a terrifying rate.