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Rebecca Skloot reveals *The Immortal Life of Henrietta Lacks*

March 24, 2010 at 6:09 pm by [Debbie Michaud](#) in [Books](#), [Events](#), [speakeasy](#)



Rebecca Skloot (Photo by Manda Townsend)

Cancer treatments. Parkinson's disease research. Genetic mapping.

Rebecca Skloot's new book, *The Immortal Life of Henrietta Lacks*, reveals the story of the woman whose cells helped revolutionize modern medicine over the last half century. Diagnosed with cervical cancer in the early '50s, Lacks sought treatment at Johns Hopkins University. There, a doctor took some of Lacks' cells and created the first immortal human cell lines, aka HeLa cells. A commodity that would be bought and sold regularly within the scientific community, Lacks' family wasn't informed of HeLa cells' existence until more than 20 years after her death. Skloot's book (11 years in the making) uncovers Henrietta's story and the monumental impacts a few tiny pieces of her left on modern science.

Skloot visits Atlanta this weekend to offer Spelman's convocation keynote Thurs., March 25 as well as book signings and author appearances around town Thurs.-Mon. at the Morehouse School of Medicine, the Atlanta Rotary Club and the Emory Center for Ethics. [Event details available on the author's website.](#)

Who is Henrietta Lacks?

Henrietta Lacks was a poor African-American tobacco farmer from Virginia. She got cervical cancer in 1951 and went to Johns Hopkins Hospital where doctors took a piece of her tissue without her knowledge, her cervical cancer tissue. Her cells became the first ever immortal human cell lines.

When you say immortal human cell lines, what exactly do you mean?

A line of cells that grows in the lab indefinitely. They will grow forever as long as you feed them, keep them at the right temperature, and clean them. [They are] cells that grow in the lab that scientists can study, and they are one of the most important things that happened in science. They were used to develop pollen vaccines. They went on space missions to see what would happen to human cells in zero gravity. They were the first cells cloned. Some of the first genes ever mapped. There is no limit to the science of these cells. It can go on and on.

Would you talk a little bit about your background and how you came to encounter the story of Henrietta Lacks?

I learned about it when I was 16 in a basic biology class. My teacher said that they were the first immortal cell line and they were hugely important to science. They came from this woman in 1951 and she's been dead basically ever since. Her cells outlived her and they've grown. Science teachers love to say that there are more cells now than there ever was of her.

For some reason, my teacher knew her name and he knew that she was black and that was it. It grabbed me so I went up to him after class and asked, "What else do you know about her? Why do we only know that? Does she have any kids?" He just said that nobody knows. I was planning on

becoming a vet — I had no interest in writing — but through different projects on her in science classes and other various things, eventually I started writing. I realized I could start tracking down her kids and the story myself.

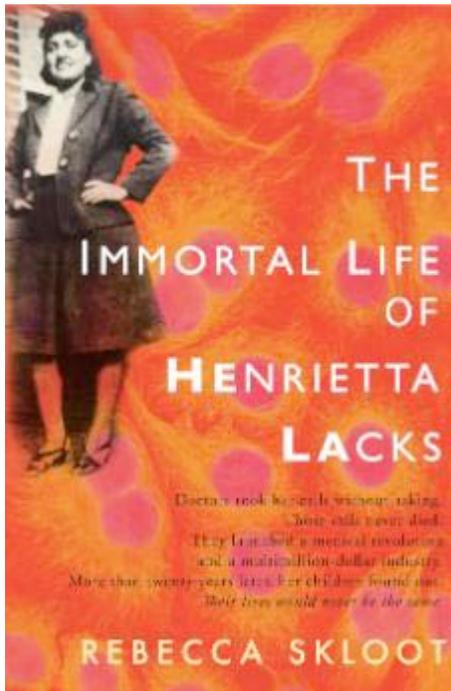
Lacks' cells were taken from her without her or her family's consent in the early '50s. What kind of privacy and ethics laws and regulations were — or were not, as the case may be — in place at the time?

There were none. It was standard practice at the time to take tissues or a lot of other things. We didn't even have the idea of informed consent. The term informed consent was not even part of the medical world. There were practices in place of patient privacy and no one ever thought of that in respect to tissues that are disembodied from a person. We didn't know what we could learn from a tissue. They didn't even know what DNA was.

Now, in a lot of ways, things haven't changed that much. There are very strict rules in place for patient privacy. You would never name a tissue after a person like hers was. Consent is required to do certain kinds of research on tissues. If a scientist comes to you and takes tissues specifically for research they have to get permission but there is a hole. Most people in the U.S. have their tissues being used, on file, somewhere because they don't really realize it. You sign a form when you go to the doctor saying, "My doctor can disclose of my tissues any way he sees fit." Once that happens, your name is stripped from it and there is no consent required for most tissue research today.

Did her story have anything to do with a creation of ethics/privacy laws? As far as consent?

We really don't have them now. There is a chance that it might. The consent stuff, most tissue research does not require consent. If it's been removed from your body for any other reason, for a basic biopsy or a diagnostic test, they go into these bio banks. Once they're there, since the researchers don't have first hand contact with the people, there is no consent required for that research. There is a lot of other ways that the tissue is used in research with that consent. There was a point and time in the '60s when there was research done using her cells could help lead to the process of IRBs where scientists have to get approval from the institute review board to do research on people and not just tissues. That came from research we've done on cells but there has not been any regulatory change due to her story specifically.



What role did race play in the event?

They were taking tissues from anyone who came into the hospital; black, white, whatever. The ward where Henrietta was treated was the public ward at Hopkins and she went there because she was black and this was the only way they could get treated. It was a charity hospital so the majority of the people there were black or poor or both. So you can't separate race from the story, but historically it's been held up as a story of a racist white scientist that sort of targeted her because she was black and knew that her cells were valuable and stole them from her; that they didn't treat her cancer in order for the cells to grow. None of that is true.

How and when did Lacks' family find out her cells had been taken and learn the extent to which they had been used? What was their reaction?

They found out in the early '70s when scientists tracked down her kids in order to do research on them to understand the cells. So the story is as much about what happened with her kids as it is about her. Her kids were used for research for their knowledge as well. Her husband got a phone call one day and he had segregated education so he didn't understand what a cell was. How he understood the call was: "We've got your wife. She's alive and in our laboratory. We've been doing research on her for the last 25 years and now we have to test your kids to see if they have cancer." Which wasn't what the scientist said at all but the family didn't understand and the scientist didn't realize that the family didn't understand so they just got sucked into this world of research without really knowing it. It went on for decades and had a pretty dramatic effect on them.

Henrietta's daughter, Deborah, played a particularly important role in piecing together the story of Henrietta and her cells. Would you talk about your relationship with Deborah and the process of researching the story?

When I first called in the '90s, the family still didn't know what a cell was. No one had explained to them what was going on and they had no interest in talking to me. It took me about a year and a half to win their trust and convince them to talk to me. Part of how I did that was to tell Deborah, "Hey, I will share with you any information I find. By doing this, you can learn about your mother as well." She was 2 when her mother died and she didn't know her at all and she really wanted to. She was very desperate to know who her mother was and what happened to her and what these cells were. So one of the ways that I got her to be interested in me was invite her to do research with me. I told her, "I'm not trying to hide anything from you. I will let you know anything that I find." So in the end, we did that and one of the things we did together was I took her into the lab to see her mother's cells for the first time and we did various things like that. We traveled a bit. We would go down to Virginia, where her mother was from and that became a part of the story.

Would you discuss your reasoning for writing yourself into the story?

I had no interest in being in the story at all. I said this was their story, not my story. And as a teacher I harp on my students about putting themselves in other people's stories. Slowly I realized I was writing myself into the story — I had become a character in their story because I come from a long line of people who want something from them and I had, at times, had drastic impacts on their lives.

Deborah would come and travel with me and some of the information that she heard was really traumatizing for her and we developed a relationship. Before I put myself in the book, she recognized it and said, "Don't you make me be in this story all by myself." It would be dishonest to leave myself out because I had such an impact on their lives in some ways positive and some ways not so positive. So I realized that it was part of the story and I had to include it.

I also talked to a lot of my friends during the process and one in particular told me their resistance to you is part of the story. How they responded to me really illustrated how traumatized they really were by everything that happened before, in a way that would've been difficult to really illustrate how their fear and distrust were heightened and it reached it peak when I got there so I felt like that needed to be in there.

How did this change you? And the family?

It was an 11 year process and it's changed me and affected me in ways I'll be trying to figure out for years. I grew up writing this story. I was in my 20s when I started and I had to think a lot about what is to be a journalist. I came from a non-religious background, a completely different culture than Deborah. The religion was so surprising to me. It was such an important part of their story and their lives and their understanding of the self. I just knew nothing about it and in the process of learning I read the Bible for the first time. I went to the church with them and I saw faith healings; things I had never been exposed to. I spent a lot of time learning about what their religion and spirituality meant for them and how that interacted with the science.

I think I learned a lot about religion just in general and about lots of different ones and the roles they play in people's lives and the ways they can be incredibly positive and helpful. With the family that's a lot of how they came to terms with what happened with the cells: They believe she was chosen and came back as an angel in these cells to cure diseases. In terms of the family, it's still happening. They are still responding to the book and there are now generations of Lackses that have read the book. Several of them have read it many times. The grandchildren have been reading the book out loud to their parents cause they don't read so much so that's been a great thing for them. Now they're able to see the full story — what are these cells and how are they used. To see how people are responding to the story serves as some kind of validation to what they've been through that they've never gotten before.