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Nook Book Club Kit Discussion Guide

The Immortal Life of Henrietta Lacks
by
Rebecca Skloot
(Amy Einhorn Books: New York, 2009)

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 other publications. She specializes in narrative science writing and has explored a wide range of topics, including goldfish surgery, tissue ownership rights, race and medicine, food politics, and packs of wild dogs in Manhattan. She is the guest editor of *The Best American Science Writing 2011*, a contributing editor at *Popular Science* magazine, and has worked as a correspondent for WNYC's *Radiolab* and PBS's *Nova ScienceNOW*.

Skloot served for eight years on the Board of Directors of the National Book Critics Circle, where she was a vice president and judge for their yearly book awards. She has a B.S. in biological sciences and an MFA in creative nonfiction. She financed her degrees by working in emergency rooms, neurology labs, veterinary morgues and martini bars. She has taught creative writing and science journalism at the University of Memphis, the University of Pittsburgh, and New York University. She currently gives talks on subjects ranging from bioethics to book proposals at conferences and universities nationwide.

Skloot lives in Chicago. She regularly abandons city life to write in the hills of West Virginia, where she tends to find stray animals and bring them home. [From author's web site]

Summary:

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 effects of the atom bomb; 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? [From author’s web site]

Questions:

1. Start by unraveling the complicated history of Henrietta Lacks's tissue cells. Who did what with the cells, when, where and for what purpose? Who benefited, scientifically, medically, and monetarily?
2. What are the specific issues raised in the book—legally and ethically? Talk about the 1980s John Moore case: the appeal court decision and its reversal by the California Supreme Court.
3. Should patient consent be required to store and distribute their tissue for research? Should doctors disclose their financial interests? Would this make any difference in achieving fairness? Or is this not a matter of fairness or an ethical issue to begin with?
4. What are the legal ramifications regarding payment for tissue samples? Consider the the RAND corporation estimation that 304 million tissue samples, from 178 million are people, are held by labs.
5. What are the spiritual and religious issues surrounding the living tissue of people who have died? How do Henrietta's descendants deal with her continued "presence" in the world...and even the cosmos (in space)?

6. Were you bothered when researcher Robert Stevenson tells author Skloot that "scientists don't like to think of HeLa cells as being little bits of Henrietta because it's much easier to do science when you dissociate your materials from the people they come from"? Is that an ugly outfall of scientific research...or is it normal, perhaps necessary, for a scientist to distance him/herself? If "yes" to the last part of that question, what about research on animals...especially for research on cosmetics?
7. What do you think of the incident in which Henrietta's children "see" their mother in the Johns Hopkins lab? How would you have felt? Would you have sensed a spiritual connection to the life that once created those cells...or is the idea of cells simply too remote to relate to?
8. Is race an issue in this story? Would things have been different had Henrietta been a middle class white woman rather than a poor African American woman? Consider both the of the cell sample without her knowledge, let alone consent... and the questions it is raising 60 years later when society is more open about racial injustice?
9. Author Rebecca Skloot is a veteran science writer. Did you find it enjoyable to follow her through the ins-and-outs of the laboratory and scientific research? Or was this a little too "petri-dishish" for you?
10. What did you learn from reading *The Immortal Life*? What surprised you the most? What disturbed you the most?

[From: Litlovers.com]