Discussion Questions for The Immortal Life of Henrietta Lacks

1. Race and racism are woven throughout the book, both in the story presented and in the process of the research for the book. Skloot was yet another white person asking the Lacks family about Henrietta. How do you feel about a white woman creating the narrative of this story? How did her race help or hinder Skloot in the writing and researching of the book?

2. What role did the deferential attitude toward doctors in the early 20th century play in the interaction between Henrietta and her family and Johns Hopkins? How has that attitude toward doctors changed over the decades? Do patients’ socioeconomic differences affect the relationship today?

3. Henrietta Lacks died in 1951, but her cancer cells are still alive today. Do you think they carry some essence of Henrietta? How do you think you would perceive cells from someone close to you that grow in culture in a laboratory...or is the idea of cells simply too remote to relate to?

4. In the years since the uniqueness of Henrietta Lacks’s cells were discovered, others have been identified with cells that are valuable on the research market. In Chapter Five, Skloot details the history of John Moore, whose cells produced rare proteins, and Ted Slavin, whose cells produced valuable antibodies. All three cases are quite different in many ways, including how their doctors used the information. Should individuals be able to profit from their own cells? Should their doctors? With consent?

5. The passage in which the initial fated cells were removed from Henrietta Lacks’s body reads as follows (see page 33):

   “With Henrietta unconscious on the operating table in the center of the room, her feet in stirrups, the surgeon on duty, Dr. Lawrence Wharton, Jr., sat on a stool between her legs. He peered inside Henrietta, dilated her cervix, and prepared to treat her tumor. But first – though no one had told Henrietta that TeLinde was collecting samples or asked if she wanted to be a donor – Wharton picked up a sharp knife and shaved two dime-sized pieces of tissue from Henrietta’s cervix: one from her tumor, and one from the healthy cervical tissue nearby. Then he placed the samples in a glass dish.”

Bearing in mind that those two tissue samples removed from Henrietta were not removed in an attempt to treat her cancer, but rather purely for purposes of research, was it wrong for the doctor to remove the sample tissue in the first place? Was it wrong for Dr. Gey to collect those samples for the purpose of trying to grow them in controlled conditions? Does the end – i.e., the immeasurable benefit to humankind resulting from those tissue samples – justify the means – i.e., removing tissue from a person without their consent or knowledge? What does this book tell us about the history of science and how science has progressed since the 1950s?
6. If you discovered that tissue routinely removed from your body at some point in the past went on to significantly benefit science and research, would you feel that you should somehow be compensated? What do you think is more important – a person’s personal rights over their own tissue, or contributing to science and research for the benefit of all humankind? The RAND corporation estimates that 304 million tissue samples, from 178 million are people, are currently held by labs.

7. Was it a good thing for the members of the Lacks family that the author wrote this book?

8. Was the presence of the author in the book disruptive or appropriate?

9. This book combines two different stories: a narrative describing the fate of the Lacks family and a history of developments in cell biology and medical research and a consideration of the ethical issues involved in the use of tissues and cells taken from patients during diagnostic procedures. How successfully are these stories woven together?

10. What is your opinion on the needs of scientific research versus the ethical rights of individuals?

11. What are the differences between moral rights and legal rights?

12. What obligations and responsibilities do citizen have towards the perpetuation of their freedom?

13. What is the difference between social injustice and legal injustice?

Sources
http://rebeccaskloot.com/the-immortal-life/reading-group/