To assist the co-facilitators, the First-Year Advisory Board compiled a list of discussion questions, in whole or part, from a variety of book discussion group lists (indicated below), with modifications to fit the IWU Summer Reading Program.

²http://www.ncsu.edu/uap/reading/docs/HeLa-Discussion-Questions.pdf
⁴http://www.library.ncifcrf.gov/bookclubdis/hela.aspx

It is recommended that groups first take time to discuss the questions in Section 1 that students were asked to print out and respond to as they were reading the book over the summer. Next, it is recommended that groups choose from the additional discussion questions in Section 2. However, please feel free to develop additional questions with your fellow co-facilitators.

SECTION 1: General questions to guide reading

1. The Immortal Life of Henrietta Lacks is the story of an African American woman and her family that touches on many big issues: bioethics, racism, poverty, science, faith, and more. What threads stand out to you and why? ¹

2. 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? ¹

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? ³

4. 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? ⁵

SECTION 2: Specific questions to guide group discussions

1. A week after you finished reading the book, did you remember how cells divide? Do you now have a better understanding of cell biology? Either way, does it matter to you? ¹

2. 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 doctors be able to profit from their own cells? Should their doctors? With consent? Do you think Henrietta would have provided consent for her cells to be taken and used had she been asked? ¹

3. Making health care affordable to all Americans has been a recent political focus. What does the story of Henrietta Lacks and her family add to this discussion? ¹

4. If Henrietta had been treated today, what would be similar and/or different about her treatment? ²

5. How might have Henrietta’s children’s lives been different had she been given credit and acknowledgment for her cells at the time they were taken? ²
6. 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 taking 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?¹

7. 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?³

8. 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?³

9. When HeLa cells started to be sold, do you think that Dr. Gey should have stepped in to assure that Henrietta Lacks' family was compensated in some way? Do you think they should be compensated at all?⁴

10. Do you think the doctors who allowed patients to be involved in potentially harmful experiments without their knowledge were complying with their Hippocratic Oath to "do no harm"?⁴

11. 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?⁵

12. 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 anesthetic 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 have given 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?⁵

13. 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?⁵

14. 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?⁵

15. 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 Lackses’ response to and interpretation of the scientific information they receive about HeLa? How does Skloot’s attitude toward religious faith and science evolve as a result of her relationship with the Lackses?⁵