Henrietta Lacks
Discussion Questions for US101 Seminar

Identity:
Mary Kubicek, the lab assistant who first cultured Henrietta’s cells, identifies the moment in the morgue in which she confronted Henrietta’s humanity, saying “When I saw those toenails ... I nearly fainted. I thought, Oh jeez, she’s a real person” (90-91). What is it that defines individuality? On the other side, what defines immortality?

Taking into consideration that our identities are shaped by where we are from, the environment we grow up in, and the time in history in which we are living – how do those factors shape Deborah’s identity considering that Deborah is living in a post-Civil Rights world and her mother lived in a pre-Civil Rights world?

Recently in the news, there has been a lot of discussion about the “Black Lives Matter” movement (blacklivesmatter.com), particularly in relation to the tension and violence that has occurred between African Americans and police. How might we try to understand how this movement has come into existence in our current time, when considering the circumstances surrounding the Henrietta Lacks story?

Ethics:
The book opens with Deborah’s voice stating, “if our mother cells done so much for medicine, how come her family can’t afford to see no doctors?” Is this a tragic reality? Or do we owe something to the people who contribute to the body of knowledge in a discipline such as medicine?

In the lawsuit filed by John Moore against UCLS for “deceiving him and using his body in research without consent” (203), the question of property rights in human tissue research was confronted. Who do you think owns your human tissue? You, or the person who knows what to do with it?

Skloot explains that in the 1950s “many scientists believed that since patients were treated for free in the public wards, it was fair to use them as research subjects as a form of payment” (30). Is this ethical? Does this disenfranchise the poor or marginalized members of society and their individual rights?

Considering that the HeLa cells were used to contribute to many advances in medicine, it could be argued that in the words of Spock in Star Trek II: “The needs of the many outweigh the needs of the few,” particularly, in terms of informed consent. How does this stack up against individual rights? And, how do we makes sense of it when re-reading Elie Wiesel’s quote just prior to the Prologue: “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.” Who has the right to tell those “secrets”? 
Education and Understanding:

Many of the critical moments in Henrietta’s story hinge on communication – or lack thereof. Her detailed medical chart (16) notes indicate a depth of knowledge and information regarding her conditions that do not appear to be shared fully with her. Her tissue donation is extracted without her knowledge, while she is “unconscious on the operating table” (33). We know that Henrietta was not well educated; given that, what responsibility do medical practitioners have in communicating with patients they are uncertain will understand the implications of that information?

Skloot references the “benevolent deception” (63) practice prevalent at the time in medical practice. What impact does this unquestioning acceptance have on the identity of the patient?

Skloot identifies a disconnect between communication and understanding in Lacks’ medical chart, citing doctors who wrote, “Told she could not have any more children. Says if she had been told so before, she would not have gone through treatment” (48). We are told throughout the story that Henrietta identified largely as a mother; at what price is medical treatment? How can we balance the limits of scientific understanding versus the survival from the treatment itself?

Skloot offers a vivid description of George Gey’s television appearance in 1951 (57-58), which calls to mind current examples of awkward or inaccurate translation of scientific findings to a popular audience. What responsibility does the scientist or researcher have in making that translation understood?

In several instances throughout this book, reporters approach individuals related to Henrietta’s case with the intent of making the story, and her identity public. Throughout each of these cases – even in the case of Skloot’s book – there is great tension between the right of a reporter to make Lacks’ story public (for whatever gain) and the right of the family to privacy. The family even experiences that tension within itself. What is the greater right?

In the years following Stanley Gartler’s “HeLa Bomb” (152) in 1966, Skloot writes that “Despite all of the evidence, most researchers still refused to believe there was a problem” (174). Why is it so difficult to accept evidence that challenges the status quo?

When Skloot explains to Dr. Susan Hsu the misunderstanding experienced by the Lacks family in her blood sampling for research, she responds with shock, saying “I feel very bad ... People should have told them. You know, we never knew at that time they did not understand” (189). Was it reasonable for her to expect that the family understood what they were being asked to do?

The ability for all Americans to get a college education is an issue that is consistently brought up in the political arena, especially during election season. And yet, there are always arguments that we need all parts of society (upper, middle, and working classes) in order for a society to work well. Some would say that this means, we do not need everyone to have an education. However, how does a lack of
education translate into a lack of knowledge and the ability to communicate effectively about health conditions play out in the experiences and interactions that the Lacks’s have with the medical community?