

**NMPL Book Club – November 12, 2013**

- 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?
- 2) 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?
- 3) The author notes social inequities both explicitly and implicitly. What parts of Henrietta's story might be different if she had been white? What might have been different if she had been middle or upper-middle class?
- 4) 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?
- 5) 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?
- 6) A week after you finish reading the book, will you remember how cells divide? Do you now have a better understanding of cell biology? Either way, does it matter to you?
- 7) What does this book tell us about the history of science and how science has progressed since the 1950s? After reading this book and considering the events it details, what do you think are key factors that influence scientific progress?
- 8) The book is filled with stories of people used as research subjects, sometimes without their knowledge, sometimes with ill-informed consent, sometimes *because* of their inability to understand (patients with mental illness) or resist (prisoners). Were you aware of this history before reading the book? Do you think doctors and researchers of the past had a fundamentally different view of people than they do today?
- 9) 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? Do you think Henrietta would have provided consent for her cells to be taken and used had she been asked?
- 10) How do you think Zakariyya reacted to the completed book and to the way the family was depicted? How do you think Deborah would have reacted?
- 11) One of the issues the book addresses is patient privacy. Henrietta completely lost hers long before the book was published, but also didn't get the fame her daughter, Deborah, thought she so richly deserved. Why does Deborah want fame for Henrietta?

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12) Skloot had to make a lot of choices about how she recounted Henrietta's story and how she structured the book. How does her narrative reconstruction of Henrietta's life impact the story? How do you feel about the reconstruction?

13) Skloot recounts Deborah's abuse by Galen in Chapter 15. While difficult to read, it gives the reader important information about what Deborah has been through. Why did Deborah think this part of her story was important to the overall narrative? Does it change how you see Deborah? Her father, Day?

14) In an interview with Booklist magazine, Skloot says she first heard of HeLa cells at the age of sixteen when her own father was battling a viral infection with experimental drugs administered three to four times a week. Do you think her father's illness influenced her decision to pursue this story? Might his illness and treatment have influenced what threads she included in the book?

15) 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?

**Quotes Worth Noting...**