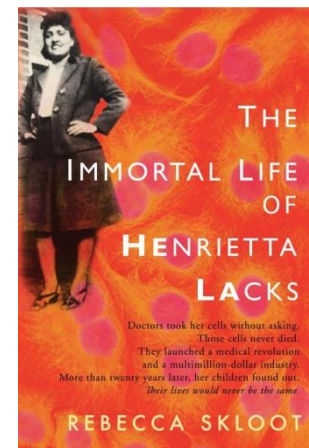


## **“Reader with a Cause” Discussion Questions for *The Immortal Life of Henrietta Lacks* by Rebecca Skloot**

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These discussion questions were prepared by the National Network to End Domestic Violence (NNEDV) for [Reader with a Cause](#), an online book club (“Group”) on Goodreads.

If you like our questions please feel free to use them – and don’t forget to join the conversation online at: [https://www.goodreads.com/topic/group\\_folder/327823?group\\_id=114966](https://www.goodreads.com/topic/group_folder/327823?group_id=114966)



### **1. Overall Thoughts & Opinions**

What did you think of *The Immortal Life of Henrietta Lacks*?

Overall thoughts about the book, Rebecca Skloot, the topic, the writing style, etc. welcome here!

### **2. The Importance of Informed Consent**

When Henrietta Lacks entered the hospital for treatment, she signed a form, “Operation Permit,” that said, “*I hereby give consent to the staff of The Johns Hopkins Hospital to perform any operative procedures and under any anaesthetic either local or general that they may deem necessary in the proper surgical care and treatment of: \_\_\_\_\_*” (on which Henrietta printed her name). (31)

Some have argued that by signing this form, Henrietta consented to all services performed on her, including the biopsy that took the cells that eventually became HeLa. However, we would argue that this form does not pass the threshold for informed consent. (Learn more here: <https://www.techsafety.org/waivers-at-a-glance/>)

We would also argue, as Skloot did, that Henrietta is a product of her time - a time in which patients, particularly people of color, "*deferred to anything [their] doctors said.*" (63) Even if she had been properly informed, she may not have had the power to consent.

What do you think?

### 3. Book vs. Movie

*The Immortal Life of Henrietta Lacks* is being made into an HBO movie (watch the official trailer here: <https://www.youtube.com/watch?v=qPDh5OwvXME>). How do you think this will translate to film? Will you tune in for it?

What do you think of the casting choices:

- Oprah Winfrey as Deborah Lacks
- Rose Byrne as Rebecca Skloot
- Renée Elise Goldsberry as Henrietta Lacks

### 4. Race

Would Henrietta Lacks have lived if she had been White? Would she have been asked before her cells were taken for research if she had been White? Rebecca Skloot says "*There's no way of knowing.*" (64)

*"According to Howard Jones, Henrietta got the same care any white patient would have; the biopsy, the radium treatment, and radiation were all standard for the day."* However, she goes on to say that *"...several studies have shown that black patients were treated and hospitalized at later stages of their illnesses than white patients. And once hospitalized, they got fewer pain medications, and had higher mortality rates."* (64)

What do you think?

### 5. Who Owns Your Cells?

Let's say you were going in for surgery to remove part of your kidney. What do you think should happen to that leftover tissue? Does it still belong to you or should doctors be able to use it for research? If a major medical breakthrough occurs from your tissue, should you be told about it? Should you benefit from it?

Do you agree that "A patient must have the ultimate power to control what becomes of his or her tissues" as the judges initially wrote in the Moore case? (205) Or do you agree that "When tissues are removed from your body, with or without your consent, any claim you might have had to owning them vanishes" as the Supreme Court in California ultimately ruled? (205)

## 6. HeLa and the Lacks Family Today

*"Them doctors say her cells is so important and did all this and that to help people. But it didn't do no good for her, and it don't do no good for us. If me and my sister need something, we can't even go see a doctor cause we can't afford it. Only people that can get any good from my mother cells is the people that got money, and whoever sellin them cells -- they get rich off our mother and we got nothing."* --Zakariyya (146-7)

Zakariyya's observation is poignant. Rebecca Skloot established the Henrietta Lacks Foundation (<http://henrietalacksfoundation.org/>) to help address this disparity.

How would you resolve this?