

# LETTER FROM THE EDITOR



“... if our mother cells done so much for medicine, how come her family can’t afford to see no doctors?”

—Deborah Lacks in *The Immortal Life of Henrietta Lacks*

If there is a book that should be required reading for everyone in healthcare, it is *The Immortal Life of Henrietta Lacks* by Rebecca Skloot (Crown Publishers, 2010). This volume should have a major impact on physicians, researchers, social workers, and those in the insurance industry, not to mention anyone who has ever been a patient. It is the story of a poor African American woman from tobacco country in Virginia in the 1950s. The story tells of how her aberrant cervical cancer took over the world. She developed cervical cancer that was so aggressive that it flourished through mutilating surgery and frying radiation. She received what would be considered—even then—third-rate medical care in the “colored ward” at Johns Hopkins because of her race. A sample of her tumor was put into culture and became the first immortalized human cell line. It was named HeLa. Blood was taken repeatedly from her and her family members for a purpose described only as “checking to see if they had cancer.” Why were these cells so important? Just for starters: they were used to generate the first polio vaccine and the first standardized culture medium; they launched an industry that sells biological specimens and has grossed countless millions of dollars over the past 50 years; they led to several Nobel prizes, an understanding of how HIV infects cells, and identification of telomerase; they increased our understanding of how genes are turned on and off, how cloning and somatic cell fusion work, how cells respond to space flight . . . need I go on? The discovery that the cells were so virulent that, through some airborne travel, they were contaminating laboratories around the world even led to discoveries including how to identify different clones of cells using G6PD screening. The uncontrolled global dissemination of her cells reminded me of the old movie *The Blob*, in which an amorphous mass was growing and consuming everything in its path, except when frozen—also the only way to halt the proliferation of HeLa cells. The biggest chunk of irony was that her cells led to the development of the human papillomavirus vaccine, now approved for preventing the very disease to which she succumbed.

Unbeknownst to Henrietta’s family, her medical records were made public. (Clearly, her case was pre-HIPAA.) The closest she came to privacy was that, for many years, the rumor was that the HeLa patient had been named Helen Lane. While numerous newspaper articles reported how hundreds of people made millions of dollars from her cells, her family remained poor and uneducated. While the lives of many others were being saved as a result of the medical

advances resulting from HeLa cell research, her family was unable to afford health insurance.

The book raises countless ethical and moral issues, which the author accurately boils down to consent and money. Whose tissue is it anyway? When you pee into a cup, does the specimen still belong to you? What if the procedure is a bit more invasive, such as venipuncture? Should patients be required to sign informed consent for future research that might use stored samples? Who should own the rewards gained from discoveries from the tissue? Although it is accepted practice to require consent for any tissue that might be considered for research now or in the future, the Federal Policy for the Protection of Human Subjects (the Common Rule) doesn’t cover tissue procured during routine care. Tissue research can escape regulation if there are no federal funds involved or there is no direct connection with the source of the tissue.

Requiring consent for anything and everything that might be done with such tissue at any time in the future would be destructive to scientific progress, and, in fact, is not even feasible. Given the anonymity imposed by HIPAA, it is also impossible to track down whoever was the source of what turns out to be valuable material and include him or her in the financial rewards. On the other hand, if patients knew that their bodily substances had the potential to turn a profit a decade later, the next logical step would be for them to start selling their blood, urine, or whatever, which—as is the case with organ donation—would be illegal, under current law. Nevertheless, as reported in *The New York Times* on May 17, 2010, a woman donated a kidney and, when the grateful recipient offered her a present, she declined. But, the donor let the recipient know that her house was in arrears and she could sure use some help. The question posed was whether the recipient was obliged to provide the financial assistance. The answer was that a gift should be considered a gift.

In the end, Henrietta’s family took the moral high ground and never sued Hopkins or anyone else who derived gain from her tissues, even though there was no compensation for what the family members considered to be illegally procured tissue. In particular, her daughter Deborah was satisfied that so much good was being done for so many. All she wanted in return was recognition for her mother. This book certainly accomplishes that goal, as well as establishes a scholarship fund for the descendants of Henrietta Lacks (HenriettaLacksFoundation.org).

Until next month . . .

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