A Lasting Gift to Medicine That Wasn't Really a Gift

By DENISE GRADY, February 2, 2010, New York Times

Fifty years after Henrietta Lacks died of <u>cervical cancer</u> in the "colored" ward at Johns Hopkins Hospital, her daughter finally got a chance to see the legacy she had unknowingly left to science. A researcher in a lab at Hopkins swung open a freezer door and showed the daughter, Deborah Lacks-Pullum, thousands of vials, each holding millions of cells descended from a bit of tissue that doctors had snipped from her mother's cervix.

Ms. Lacks-Pullum gasped. "Oh God," she said. "I can't believe all that's my mother."

When the researcher handed her one of the frozen vials, Ms. Lacks-Pullum instinctively said, "She's cold," and blew on the tube to warm it. "You're famous," she whispered to the cells.

Minutes later, peering through a microscope, she pronounced them beautiful. But when she asked the researcher which were her mother's normal cells and which the <u>cancer</u>cells, his answer revealed that her precious relic was not quite what it seemed. The cells, he replied, were "*all* just cancer."

The vignette comes from a gripping new book, "The Immortal Life of Henrietta Lacks" (Crown Publishers), by the journalist Rebecca Skloot. The story of Mrs. Lacks and her cells, and the author's own adventures with Mrs. Lacks's grown children (one fries her a pork chop, and another slams her against a wall) is by turns heartbreaking, funny and unsettling. The book raises troubling questions about the way Mrs. Lacks and her family were treated by researchers and about whether patients should control or have financial claims on tissue removed from their bodies.

The story began in January 1951, when Mrs. Lacks was found to have cervical cancer. She was treated with radium at Johns Hopkins, the standard of care in that day, but there was no stopping the cancer. Her doctor had never seen anything like it. Within months, her body was full of <u>tumors</u>, and she died in excruciating pain that October. She was 31 and left five children, the youngest just a year old. She had been a devoted mother, and the children suffered terribly without her.

Neither Mrs. Lacks nor any of her relatives knew that doctors had given a sample of her <u>tumor</u> to Dr. George Gey, a Hopkins researcher who was trying to find cells that would live indefinitely in culture so researchers could experiment on them. Before she came along, his efforts had failed. Her cells changed everything: they multiplied like crazy and never died.

A cell line called HeLa (for Henrietta Lacks) was born. Those immortal cells soon became the workhorse of laboratories everywhere. HeLa cells were used to develop the first<u>polio vaccine</u>, they were launched into space for experiments in zero gravity and they helped produce drugs for numerous diseases, including <u>Parkinson's</u>, leukemia and <u>the flu</u>. By now, literally tons of them have been produced.

Dr. Gey did not make money from the cells, but they were commercialized. Now they are bought and sold every day the world over, and they have generated millions in profits.

The Lacks family never got a dime. They were poor, with little education and no <u>health insurance</u>, and some had serious physical or mental ailments. But they didn't even know that tissue had been taken or that HeLa cells even existed until more than 20 years after Mrs. Lacks's death. And they found out only by accident, when her daughter-in-law met someone from the <u>National Cancer</u> Institute who recognized her surname and said he was working with cells from "a woman named Henrietta Lacks."

The daughter-in-law rushed home and told Mrs. Lacks's son, Lawrence, "Part of your mother, it's alive!"

When they learned that their mother's cells had saved lives, the family felt proud. But they also felt confused, a bit frightened, used and abused. It had never occurred to anyone to ask permission to take their mother's tissue, tell them that her cells had changed scientific history or even to say thank you. And certainly no one had ever suggested that they deserved a share of the profits.

Some of the Lackses later gave blood to Hopkins researchers, thinking they were being tested for cancer, when really the scientists wanted their genetic information to help determine whether HeLa cells were contaminating other cultures. When Ms. Lacks-Pullum asked a renowned geneticist at the hospital, Victor McKusick, about her mother's illness and the use of her cells, he gave her an autographed copy of an impenetrable textbook he had edited, and, Ms. Skloot writes, "beneath his signature, he wrote a phone number for Deborah to use for making appointments to give more blood."

The bounds of fairness, respect and simple courtesy all seem to have been breached in the case of the Lacks family. The gulf between them and the scientists — race, class, education — was enormous and made communication difficult.

A less charitable view is that it might have made the Lackses easier to ignore. When the family's story became known in the black community in Baltimore, Ms. Skloot writes, it was seen as the case of a black woman whose body had been exploited by white scientists.

Ideas about informed consent have changed in the last 60 years, and the forms now given to people having surgery or biopsies usually spell out that tissue removed from them may be used for research. But Ms. Skloot points out that patients today don't really have any more control over removed body parts than Mrs. Lacks did. Most people just obediently sign the forms.

Which is as it should be, many scientists say, arguing that Mrs. Lacks's immortal cells were an accident of biology, not something she created or invented, and were used to benefit countless others. Most of what is removed from people is of no value anyway, and researchers say it would be too complicated and would hinder progress if ownership of such things were assigned to patients and royalties had to be paid.

But in an age in which people can buy songs with the click of a mouse, that argument may become harder to defend.

So far, the courts have sided with scientists, even in a case in the 1980s in which a leukemia patient's spleen and other tissues turned out to be a biomedical gold mine — for his doctor. The patient, John Moore, sued his doctor after discovering that the doctor had filed for a patent on his cells and certain proteins they made, and had created a cell line called Mo with a market value estimated at \$3 billion. Mr. Moore ultimately lost before the California Supreme Court.

As Ms. Skloot writes in her last chapter, this issue is not going away. If anything, it may become increasingly important, because the scale of tissue research is growing, and people are becoming savvier about the money to be made and also the potential for abuse if tissue samples are used to ferret out genetic information.

The notion of "tissue rights" has inspired a new category of activists. The question that comes up repeatedly is, if scientists or companies can commercialize a patient's cells or tissues, doesn't that patient, as provider of the raw material, deserve a say about it and maybe a share of any profits that result? Fewer people these days may be willing to take no for an answer.

This article has been revised to reflect the following correction:

Correction: February 4, 2010

The Second Opinion column on Tuesday, about Henrietta Lacks, who unknowingly contributed cancer cells to medical researchers before her death in 1951, misstated the surname of one of her children at one point. As noted elsewhere in the column, she is Deborah Lacks-Pullum, not Pullum-Lacks.