If you go to the hospital to have your appendix removed, your parents will sign a form giving permission for the surgery. This form may say that tissue taken during surgery could be used for scientific research. Most likely, your parents quickly sign the form without reading it so you can get to the O.R., stat! You’re doubled over in pain and don’t really care what happens to that nasty appendix anyway, right?
Henrietta Lacks died too young, but her cells live on. These cells, known as HeLa, have played a role in many scientific and medical breakthroughs for over 60 years and counting.
But what if a researcher uses your appendix cells to find a cure for cancer? What if that cure generates millions of dollars for a drug company? Should you receive payment for the use of your cells? Should you be told how your cells were used? Are they still “your” cells once they’re removed from your body?

THE IMMORTAL HELa CELL LINE

In 2010, Rebecca Skloot published *The Immortal Life of Henrietta Lacks*, a true story involving science, bioethics, race, and family. It is also the saga of Lacks’ immortal cell line! But we’ll get to that a little later.

Henrietta Lacks was a poor, black tobacco farmer who lived near Baltimore, Maryland. At 31, she was the mother of five children and had advanced cervical cancer. She had surgery in the free care ward for “colored” people at Johns Hopkins Hospital. Despite treatment, Lacks’ cancer spread. She died in the fall of 1951.

Lacks had signed an “operation permit” giving permission for the surgery, but she never agreed that the surgeon could remove small sample tissues (groups of cells) from her body to study her cancer. Without Lacks’ knowledge, the surgeon took samples. At the time, this was common practice. Dr. George Gey, a tissue culture researcher at Johns Hopkins, received them. The samples were simply marked “HeLa.”

Now for the cool “immortal cell” part.

Gey had spent years trying to find a way to keep human cells alive in a lab, but they all eventually died. Scientists place extracted tissues in nutrient-rich petri dishes. This is called growing cells “in culture.” The nutrients feed the cells so they will grow and multiply—for a while.

Lacks’ cancer cells were different. They reproduced every 24 hours, and they kept going. They continue to multiply to this very day! That’s right, as you’re reading this sentence, Henrietta Lacks’ cells are reproducing
somewhere in the world. Her cells have lived in labs longer than they lived inside her body.

**TINY CELLS AND BIG BUSINESS**

In 1951, a polio epidemic in the United States was nearing its peak. Dr. Jonas Salk from the University of Pittsburgh was close to developing a vaccine that, if it worked, would protect millions of children from polio—a disease that causes paralysis or even death.

Salk needed a huge number of cells for field trials to test the vaccine’s safety and effectiveness. In his trials, he exposed cells to live poliovirus and samples of vaccinated blood. If the vaccine worked, it would prevent the virus from infecting the cells.

When word of the amazing HeLa cells spread throughout the medical community, scientists knew they would be perfect for the vaccine trials. The Tuskegee Institute in Alabama established the HeLa Distribution Center. The Center was actually a factory that produced 20,000 tubes of HeLa—about 6 trillion cells—every week. This was more than enough for the polio trials, so the Center began selling vials of cells to any scientist who wanted them for $10 plus shipping.

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**HeLa aids medical research on HIV.**

**1986**

**HeLa cells facilitate research on tuberculosis.**

**1993**

**The HeLa genome (its complete set of DNA) is sequenced and published without the Lacks family’s knowledge.**

**2005**

**Scientists test the effects of nanotechnology on HeLa cells.**

**2009**

**By this date, more than 60,000 scientific articles have mentioned HeLa cells.**

**2013**

**The National Institutes of Health, the U.S. agency for medical research, and the Lacks family agree on rules that include the family in decisions regarding the cell line genome.**

**2030**

**What if, thanks in part to researchers using the HeLa cell line, a breakthrough cancer treatment identifies and removes the disease while cancer cells are at their earliest stage of development?**
HENRIETTA’S FAMILY LEARNS OF HER LEGACY
By 1973, HeLa cells had been used not only for curing polio, but also in research on hundreds of diseases, including leukemia, lung cancer, and Parkinson’s. HeLa even went into space on both Russian and American missions! But 22 years passed after Lacks’ death before her husband and children learned about her immortal cells.

In June of 1973, researchers wanted to study the Lacks family DNA. They went to Henrietta Lacks’ hometown near Baltimore to take blood samples from her husband and adult children. The family members agreed to give blood, but the conversation was hard to follow. They weren’t familiar with the scientific terminology being tossed around.

At first, the family thought the blood samples were to find out if they had the same cancer that Henrietta had. The doctors’ complicated explanations stirred up confusion and fear. Were they giving blood, or were they being injected with cancer?

When the doctors described their work to clone Henrietta’s cells, the family imagined people walking around that looked like their mother. When they said her cells had been on space missions and were used in atomic bomb testing, the children envisioned pieces of their mom on the moon or being blown up somewhere. They wondered how parts of their mother could still be alive. Was she not resting in peace?

HELA, HEALTHCARE, AND PROFIT
Scientific research relies on donated tissue to develop medical advances that benefit humankind. But Henrietta Lacks’ family could not afford some of the very drugs created by the research accomplished with HeLa cells. Her family remained poor and uninsured, while cell banks and pharmaceutical companies generated huge profits from the HeLa cell line. (A vial of HeLa sells online today for around $400.) Is this OK?

Lacks’ family has never received money directly from institutions or companies that have benefitted from HeLa cells, and they probably never will. Paying the Lacks family would set a legal precedent, or example, for paying millions of other people whose cells were similarly extracted and used in research.

Lacks’ story is remarkable not only because of her immortal cells, but also because it has sparked discussions about patients’ rights, medicine and money, and what’s right and wrong regarding human cells. The Lacks family has come to be proud of Henrietta’s scientific contributions. Today, many people celebrate her life and legacy.

Leanne Longwill is a freelance writer in Pittsburgh, Pennsylvania. She likes to read and write about science.

THE HENRIETTA LACKS FOUNDATION
It took Rebecca Skloot over 10 years to write The Immortal Life of Henrietta Lacks and, during that time, she became very close with Lacks’ descendants. To honor the family and recognize one woman’s contribution to science, Skloot created The Henrietta Lacks Foundation, a nonprofit organization that grants money to the Lacks family and other similar, needy families.

To qualify for a grant, an applicant must prove financial need and have made, or be related to someone who has made, a significant contribution to scientific research without any personal benefit.

The foundation has provided tuition and books for Lacks’ grandchildren and great-grandchildren. They attend high schools, colleges, graduate schools, and trade schools. The foundation has also helped the family with medical and dental expenses. Anyone can contribute to the foundation, including the scientists, universities, and corporations who have benefited from Lacks’ cells.