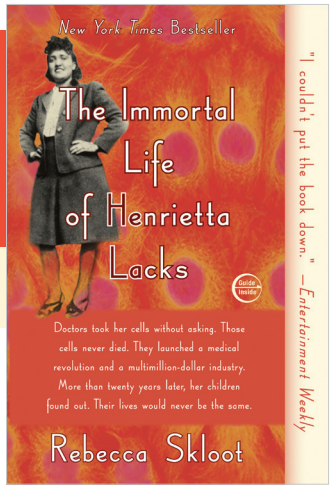
The Immortal Life of Henrietta Lacks
Rebecca Skloot

A Reader's Guide



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Timeline

1889.....Johns Hopkins Hospital is founded.

1912.....Alexis Carrel claims to have successfully grown "immortal" chicken-heart cells.

1920.....Henrietta Lacks is born in Roanoke, Virginia.

1947.....The Nuremberg Code, a set of ethical standards for human experimentation, is produced as the result of a trial against several Nazi doctors who conducted experiments on prisoners during World War II.

1951.....George Gey successfully cultures the first immortal human cell line using cells from Henrietta's cervix. It is given the name HeLa after the first two initials of Henrietta's first and last names.

1951.....Henrietta Lacks dies of an unusually aggressive strain of cervical cancer.

1952.....HeLa cells become the first living cells shipped via postal mail.

1952.....The Tuskegee Institute opens the first "HeLa factory," supplying cells to laboratories and researchers and operating as a nonprofit. Within a few years, a company named Microbiological Associates would begin selling HeLa for profit.

1952.....Scientists use HeLa cells to help develop the polio vaccine.

1953.....HeLa cells become the first cells ever cloned.

1954.....The pseudonym "Helen Lane" first appears in print as the source of HeLa cells.

1954.....Chester Southam begins to conduct experiments without patient consent to see whether or not injections of HeLa cells could cause cancer.

1957.....The term "informed consent" first appears in court documents.

1965.....HeLa cells are fused with mouse cells, creating the first animal-human hybrid cells.

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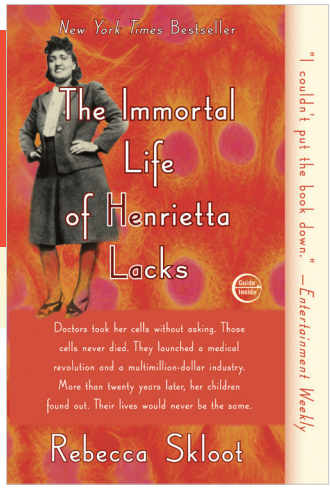

1965.....The Board of Regents of the University of the State of New York finds Southam and a colleague guilty of unprofessional conduct and calls for stricter guidelines regarding human research subjects and informed consent.

1966.....To ensure adherence to the new guidelines for research involving human subjects, the National Institutes of Health begins requiring the approval of Institutional Review Boards for any research they fund.

1966.....Stanley Gartler drops the "HeLa bomb" and proposes that HeLa cells have contaminated numerous cell lines.

1970.....George Gey dies of pancreatic cancer.

1971.....In a tribute to Gey, Henrietta Lacks is correctly identified for the first time in print as the source of HeLa.

1973.....The Lacks family learns for the first time that Henrietta's cells are still alive.

1973.....Researchers from Johns Hopkins take samples from Henrietta's children to further HeLa research, without informed consent.

1974.....The Federal Policy for the Protection of Human Subjects (the Common Rule) requires informed consent for all human-subject research.

1975.....Michael Rogers publishes an article about HeLa and the Lacks family in *Rolling Stone*. The Lacks family learns for the first time that Henrietta's cells have been commercialized.

1984.....John Moore unsuccessfully sues his doctor and the Board of Regents of the University of California for property rights over his tissues. Moore appeals the decision.

1985.....Portions of Henrietta's medical records are published without her family's knowledge or consent.

1988.....The California Court of Appeals rules in John Moore's favor, saying that patients must have the power to control what becomes of their own tissues. Moore's doctor and the University of California appeal.

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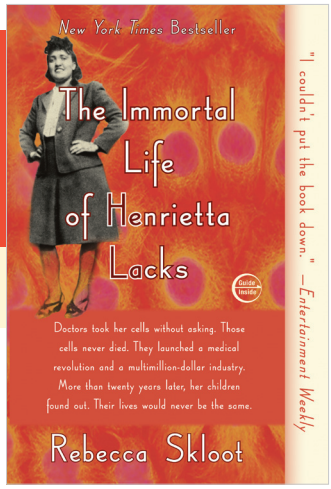

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1991.....The Supreme Court of California rules against John Moore, saying that once tissues are removed from the body, with or without consent, a person no longer owns those tissues.

1996.....The Health Insurance Portability and Accountability Act makes it illegal for health-care providers or health insurers to make personal medical information public.

1999.....The RAND Corporation publishes a report with a "conservative estimate" that more than 307 million tissue samples from more than 178 million people are stored in the United States alone. The majority of the samples were taken without consent.

2005.....Members of the Native American Havasupai tribe sue Arizona State University after scientists take tissue samples the tribe donated for diabetes research and use them without consent to study schizophrenia and inbreeding.

2005.....Six thousand patients join a lawsuit against Washington University, demanding that the university remove their tissue samples from its prostate cancer bank. Two courts later rule against the patients.

2005.....By this date, the U.S. government has issued patents relating to the use of about 20 percent of known human genes, including genes for Alzheimer's, asthma, colon cancer, and, most famously, breast cancer.

2006.....An NIH researcher is charged with violating a federal conflict-of-interest law for providing thousands of tissue samples to the pharmaceutical company Pfizer in exchange for about half a million dollars.

2009.....The National Institutes of Health invests $13.5 million to develop a bank for fetal blood samples.

2009 .....Parents in Minnesota and Texas sue to stop the nationwide practice of storing and conducting research—without consent—on fetal blood samples, many of which can be traced back to the infants they came from.

2009.....More than 150,000 scientists join the American Civil Liberties Union and breast cancer patients in suing Myriad Genetics over its breast-cancer gene patents. The suit claims that the practice of gene patenting violates patent law and has inhibited scientific research.