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# HeLa100: The history and ethics of HeLa cells



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She/her  
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# Henrietta Lacks

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August 1, 1920 – October 4, 1951

Born in Virginia

Worked as a tobacco farmer from a young age

Married in 1941 and moved to Connecticut

Had 5 children with her husband David Lacks

Went to John Hopkins Hospital due to a 'knot' in her womb

Diagnosed with cervical cancer

While receiving treatment, her doctor took tumour samples which went on to become the HeLa cell line



# HeLa cell line

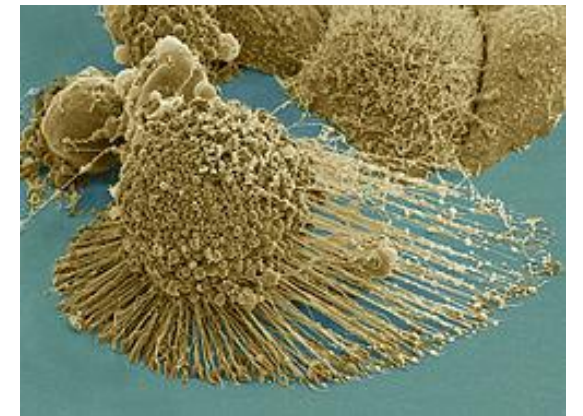
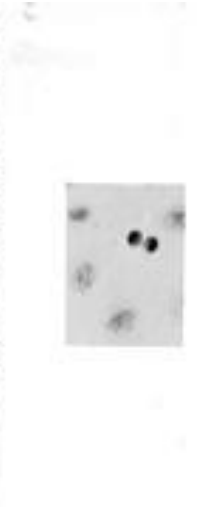
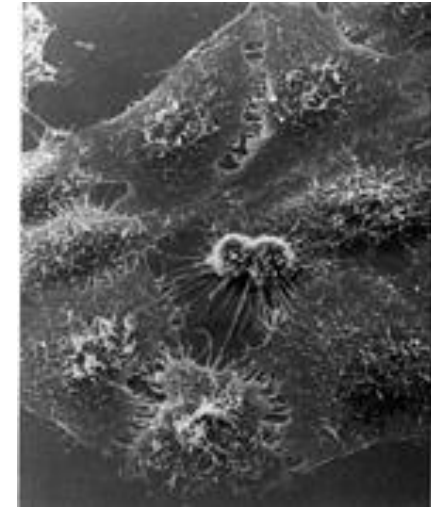
Developed by George Otto Gey and Mary Kubicek

The first immortal human cell line

Widely distributed to aid in research

- Polio vaccine testing
- The link between HPV and cervical cancer
- Effective techniques for counting chromosomes
- Effects of zero gravity on cells
- Cancer, infection, toxins, ageing

Over 11,000 patents and 110,000 papers  
reference HeLa cells



# Informed consent

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- Ca. 1910-70, researchers would regularly obtain tissue samples from surgeons
- Consent for the use of tissue samples was not considered necessary by researchers or the public
  - “Human embryos ending their existence at London hospitals are providing scientists with the means of making a vaccine against the common cold.” *The Guardian*, July 26, 1961.
- Backlash against abortion legalisation and unethical research in the 70s
  - In the 1950s and 60s, Chester M Southam injected HeLa cells into patients’ skin without their informed consent
- Increased genetic understanding
- Commercialisation of cells
  - *Moore v. Regents of the University of California*

# Racism in medical research

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- J Marion Sims - father of modern gynaecology
  - Developed surgical techniques by operating on enslaved black women without anaesthesia in the 1840s
- Tuskegee Syphilis Study
  - A 40 year study on the progression of syphilis in 600 Black men
- Forced sterilisation
  - In a 45 year period, the North Carolina Eugenics Board oversaw sterilisation of 7,600 women, 5,000 of whom were Black
- Clinical trials
  - Analysis of 41 “exception from informed consent” trials in the 2000s in the USA showed 29% of participants were Black
  - In the USA, Black people are the ethnic group with the lowest rate of participation in clinical trials

# The Lacks family

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- Poor communication from researchers
  - Requests for blood samples in the 1970s shocked and distressed family members
- Privacy concerns
  - Henrietta Lacks' full name was released on George Gey's death without consulting her family
  - In 2013, researchers published the whole HeLa cell genome
- Input into research
  - Since 2013, anyone who wants to use HeLa cells on an NIH grant needs approval from a committee including 2 members of the Lacks family
- Lack of compensation
  - HeLa cells are a huge industry and many of her descendants lack access to health care

# What should scientists do now?

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- Use alternatives
- Compensation
- Acknowledgement

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Discussion time!



## Further reading

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- *The Immortal Life of Henrietta Lacks* by Rebecca Skloot
- [What HeLa Cells Are and Why They Are Important](#)
- [A Troubled Past? Reassessing Ethics in the History of Tissue Culture](#)
- [Henrietta Lacks: What to Know About Her 'Immortal' Cells, and Why Her Story's an Example of Racism in Medicine](#)
- [Restoring trust in medical research among African-American](#)
- [Henrietta Lacks: science must right a historical wrong](#)