



Anti-Discrimination Working Group

Thursday, 22 February 2024
9.30, NCRR main meeting room (and online)

How are you feeling today?



Agenda

1. First impressions (5 min)
2. Summary of the book (10 min)
3. Discussion (30 min)
4. Ideas for next meeting (5 min)



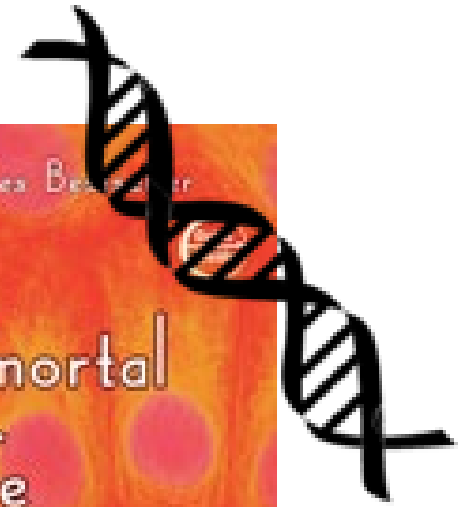
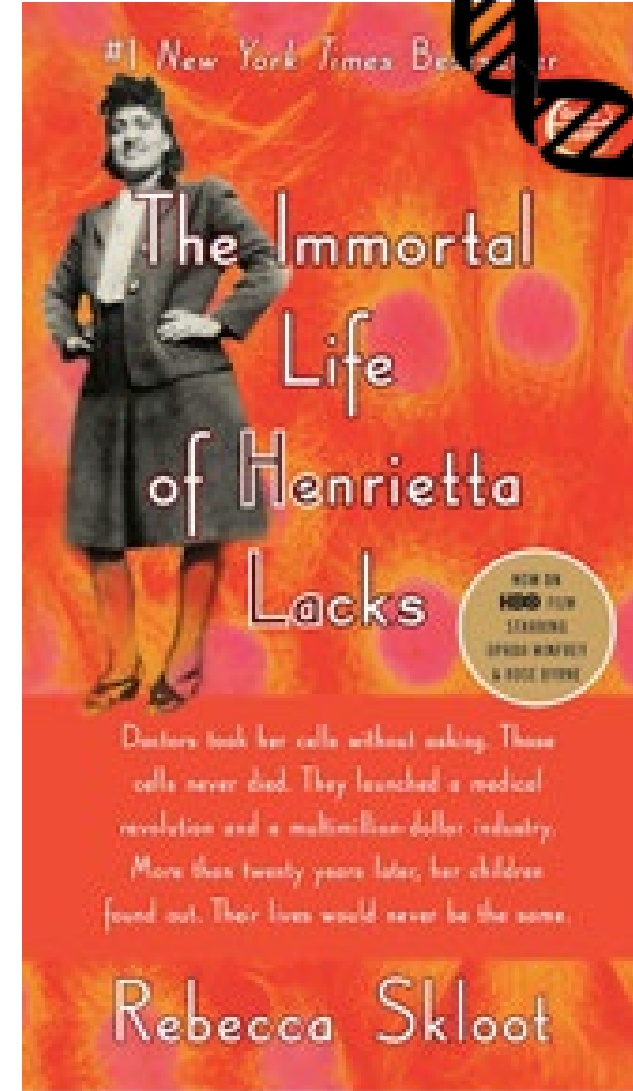
Aims of the group

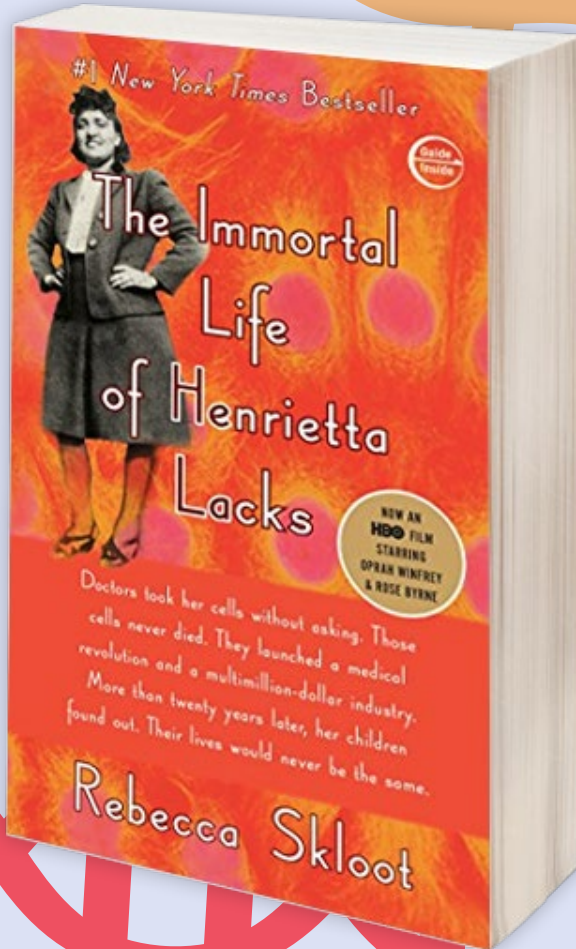
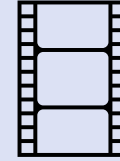
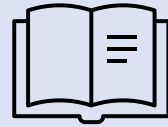
1. To strive for **equality**
2. To strive for **diversity**
3. To be **open & transparent**
4. To be mindful that **the topics we discuss may be triggering and upsetting**, impacting on people in different ways.
 - This is not a passive intellectual topic. It takes time to install the correct support and find solutions. This is a learning process.
5. To discuss ongoing issues with **discrimination in research**
6. To recognize **harmful structures and practices** of discrimination in research
7. To **advocate for changes** that promote equity in research

About the book

- Non-fiction book about **Henrietta Lacks** and the immortal cell line known as **HeLa***
- Published in 2010 by Rebecca Skloot
- Skloot conducted research and worked with Lacks' family to write the book
- Deals with ethical issues of race and class in medical research

*came from Lacks's cervical cancer cells in 1951





Did you enjoy reading the book?

listening to the audiobook?

watching the movie?

reading the summary?

Why?

Easy to read? Balanced?

Detailed? Moving?

What was most noticeable?

What do you expect?



Who was "Helen Lane"?



- Henrietta Lacks

- Born Loretta Pleasant in Roanoke, Virginia in 1920
- Sent to live with grandfather after mother died
- Family = tobacco farmers
- African-American
- Married to David "Day" Lacks
- Mother of 5 children (daughter Elsie had epilepsy)
- Loved dancing
- Often took care of others
- Delayed telling family and friends about her illness





<https://grammargardener.weebly.com/cast-of-characters-the-immortal-life-of-henrietta-lacks.html>

Summary – part 1/3

- 1951: Henrietta Lacks admitted to the “colored” section of Johns Hopkins Hospital to treat “knot” on her cervix.
 - Signed a consent form to get any surgery necessary to treat her cancer.
- The treating gynecologist took a sample of her cervical cells, both cancerous and healthy, and gave them to George Gey, who was collecting tissue samples from all cervical cancer patients.
- The cell culture from Henrietta’s cervical cancer cells survived and grew quickly, a first in the world of human cell culturing.
- Despite surgery and radiation therapy, Henrietta’s cancer returned* and quickly spread. The cancer and its treatment caused her a lot of suffering.
- Henrietta’s husband consented to an autopsy after her death.

Summary – part 2/3

- Over time, for-profit cell culture labs started mass-producing HeLa cells.
- To resolve issues with HeLa cells contaminating other cell cultures, geneticists at Hopkins contacted the Lacks children to get blood samples and identify distinct genetic markers.
 - Lacks children were not informed about purpose, thought it was for cancer screening.
- 1975: Lacks family contacted by journalist after Henrietta Lacks' true name found out and learned that her cells were still alive and being used for profit.
- 1994: Media attention attracted conman Sir Lord Cofield, who posed as a lawyer wanting to help Lacks family sue Johns Hopkins Hospital.
- 1999: Rebecca Skloot tried to get in contact with Lacks family, especially daughter Deborah, to write book about Henrietta Lacks and the HeLa cell line.

Summary – part 3/3

- 2001: Deborah and Zakariyya “meet” their mother’s cells in a Johns Hopkins laboratory and visit the hospital where their sister Elsie had been institutionalized, causing emotional distress.
- Religious soul cleansing ceremony performed by a cousin to lift the burden of Henrietta’s cells from Deborah.
- Deborah decides to support her grandchildren and other family members in pursuing an education so that they can better understand what happened to Henrietta and her cells, as she herself cannot afford to get an education.
- 2009: Deborah dies as Skloot finally finishes the book.

Discussion



Ethical dilemmas and lessons learned

Informed consent

1950s	Today
There was no established practice for informed or obtained consent from cell or tissue donors.	The participation of human subjects in a research study requires their informed consent. A declaration of consent and any accompanying additional participant information must be formulated in a language that enables persons being asked to provide their consent to understand what they are consenting to.

Denmark: Cells and tissues may be collected and stored for research without explicit consent

Opt in vs. opt out

Is opt-out actually informed consent?

Ethical dilemmas and lessons learned

The Danish Neonatal Screening Biobank

iPSYCH

Storage of the blood sample

After the screening has been carried out, the sample will be stored in frozen condition at the Danish Neonatal Screening Biobank at Statens Serum Institut in locked and secure facilities. See more on ssi.dk/nyfoedte.

The sample is stored for the following purposes:

1st priority: For the use of the child and family. This might involve supplementing with other analyses that were not available at the time of birth and to make certain identification of a person, who later in life becomes the victim of an accident, natural disaster, etc.

2nd priority: To use in the ongoing quality assurance of screening of newborn babies and in the development of new analysis and screening methods.

3rd priority: To use in health research. Use for research purposes always requires the approval of the Danish National Committee on Health Research Ethics. Projects using human biological material must also be conducted in accordance with the rules set out in the Danish Processing of Personal Data Act and on the basis of the requirements laid down by the Danish Data Protection Agency (www.datatilsynet.dk). The biobank's steering committee must also approve the use of sample material for this purpose.

You have control of the sample on your child's behalf until he or she comes of age. If you do not wish the sample to be used in health research for approved purposes, you can inform the Danish Health Authority's Tissue Utilisation Register. For more information, please check sundshedsdatastyrelsen.dk.

If you do not want the sample to be stored at all, you can state this electronically via the citizen portal borger.dk, where you must use your digital signature (NemID) and choose Statens Serum Institut as recipient. The sample will then be destroyed.

Ethical dilemmas and lessons learned

The Danish Neonatal Screening Biobank

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iPSYCH

Kritik: Forskning skal være sikkert

Kontrolsjusk afføder politisk usikkerhed om et kommende Nationalt Genom Center.

AUTOMATISK OPLÆSNING

86.000 danskeres dna opbevares ulovligt i USA

11. mar 2018 kl. 06:41

Del artikel



Dine tarmbakterier har større betydning for dit liv end tidligere antaget. Foto: Steffen Ortmann / Scanpix

af Ritzau

I strid med persondataloven har Aarhus Universitet ikke ført kontrol med sikkerheden omkring dansk dna i USA.

I strid med dansk lov har Aarhus Universitet i over tre år ikke ført tilsyn med, hvem der har adgang til 86.000 danskeres dna, som universitetet har sendt til et amerikansk forskningsinstitut. Det skriver [Politiken](#).



POLITIKEN

Onsdag

DANMARK > POLITIK > RET > SUNDHED > UDDANNELSE > FORBRUG > ØKONOMI > POLITIKEN UNDERSØGER > MENU

86.000 danskeres dna opbevares ulovligt i USA

Aarhus Universitet har sendt danskeres blodprøver til USA uden at have styr på sikkerheden.

AUTOMATISK OPLÆSNING



PKU-registeret

Tilføj sprog

Artikel Diskussion

Læs Redigér Redigér kildekode Se historik Værktøjer

Fra Wikipedia, den frie encyklopædi

PKU-registeret eller **Neonatale Screening Biobank (PKU-biobanken)** er en **biobank** ved **Statens Serum Institut**, som opbevarer blodprøver fra langt de fleste nyfødte siden 1982.

Såfremt forældrene accepterer dette, bliver hælblodprøven taget 48-72 timer efter, at barnet er født, og bliver brugt til at undersøge, om barnet lider af alvorlige sygdomme, som for eksempel **fenyketonuri (PKU)**.^[1]

Blodprøven opbevares derefter i PKU-registeret, med mindre forældrene eller barnet senere anmoder om at få blodprøven destrueret, jf. Sundhedslovens § 33, hvilket der tidligere har manglet information om.^[2] Antallet af blodprøver i PKU-registeret var i 2010 ca. 2 millioner.^[3]

Det blev i 2010, i forbindelse med lovforslag om **DNA**-registrering, overvejet at bruge PKU-registeret som udgangspunkt for oprettelse af et egentligt DNA-register i Danmark.^[3] Lovforslaget bortfaldt.

Dagbladet *Politiken* afdækkede marts 2018 at 86.000 danskeres DNA fra PKU-registeret opbevares ulovligt i USA.^[4] Det er muligt at benytte sig af retten til at få egne biologiske prøver destrueret, samt at tilmelde sig Vævsanvendelsesregistret.^[5]



Blodprøve som den udtages til test og PKU-registeret fra et nyfødt barn.

Ethical dilemmas and lessons learned

Medical records privacy

1950s	Today
Patients had no right to see or retain a copy of their medical records. No laws prohibited the sharing of medical record information in connection with research.	Patients have the right to see and have a copy of their medical records. Laws regulate patient consent and the use and sharing of medical record information.

Denmark: Health data can be used for research without explicit consent.


Patients cannot obtain information about the specific analyses or projects their data was in.

What does respect for privacy involve?

Ethical dilemmas and lessons learned

Communication with tissue donors and research participants

1950s	Today
There was no established practice for informed or obtained consent from cell or tissue donors.	Strict patient consent processes for those who donate tissue and cellular materials for research are in place.



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Better Tests Better Outcomes

The world's most advanced testing for embryo health
resulting in higher pregnancy and birth rates.



Choice Over Chance™

Can polygenic scores save the world?

Problematic behavior?

Misinformation/Ignorance



Henrietta Lakes

...

Helen L

...

Henrietta Lacks



Genetic Markers as Tracers in Cell Culture^{1,2}

STANLEY M. GARTLER,¹ Departments of Medicine and Genetics, University of Washington, Seattle, Washington 98105

SUMMARY

This paper deals with the use of various levels of genic expression to distinguish between cell cultures of different origin. DNA replication patterns, variations in the types of RNA molecules synthesized by different tissues, and the persistence of certain genetic markers in cell culture are considered. It is suggested that DNA-RNA hybridization as a means of comparing tissue and cell culture RNA molecules offers a promising tool for answers to questions of tissue origin-cell culture relationships. A survey of certain genetic markers in established human cell lines revealed the possibility of a serious problem of intraspecific contamination. Eighteen established human cell lines of supposed independent origin were shown to be identical with regard to their glucose-6-phosphate dehydrogenase (G6PD) (A) and phosphoglucomutase (1) types. Since G6PD A type has been found only in Negroes, and HeLa is from a Negro and was the first established human cell line, it is concluded that these 18 human cell lines are most likely HeLa cell contaminants.—*Nat Cancer Inst Monogr* 26: 167–195, 1967.

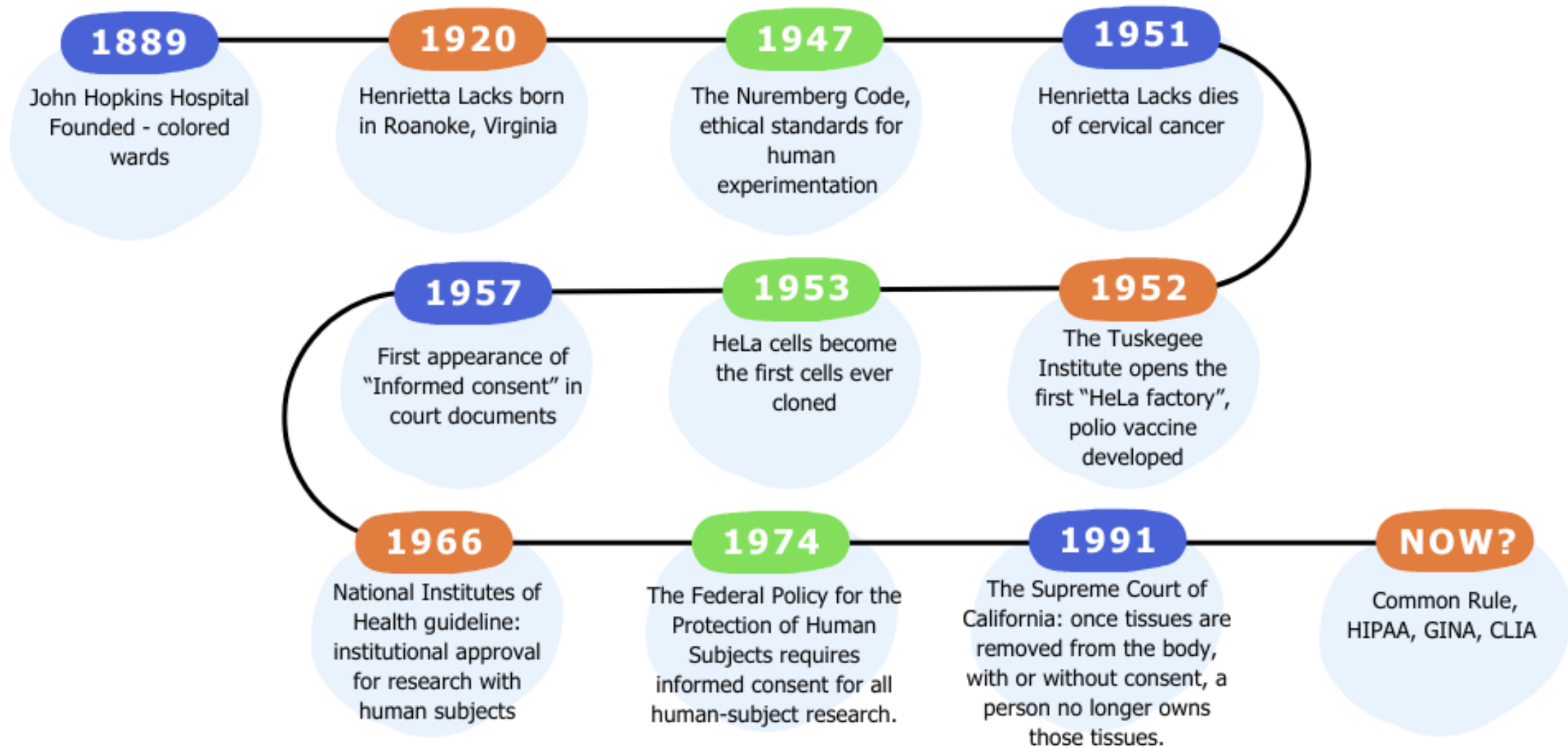
THE HOPE that cells in culture would exhibit the metabolic and immunologic characteristics of the tissue from which they were derived has met generally with disappointment. Except for neoplasms to be discussed later, cell cultures from one tissue are much the same as cell cultures from another within the same organism. I will address myself to the question of whether levels of genic expression can be used to distinguish between cell cultures of different origin. Since other speakers will discuss this question at the protein-enzyme level later in the Conference, I will confine myself to certain other aspects of genetic expression, such as



Problematic behavior?

Share knowledge with all parts of society





TRUST

Detachment from patients

- Family felt connected to material
- Researchers far removed from donors
- Commodification

Research for the societal good, but good not equally distributed

- Non-profit health research
- Family lack of access to health care
- Commercialization of cells
- Family no share in profit

Information deficit

- Benevolent deception
- Henrietta Lacks not informed
- The family was not informed
- No inclusion in process

Legal vs ethical obligations

- What is required vs what is right



- World's biggest collection of brains
- Created in Aarhus
- Collected brains from 1945-1982 from deceased psychiatric patients
- Taken without consent

- The Danish Council on Ethics created in 1987
- Council commented on collection 1991, 2006, and 2017
- Recommended 'not to contact relatives'
- Continuation of collection should be based on 'scientific value'

VIDENSKAB DK

15. NOV. 2020

På 37 år blev 9.479 hjerner skåret fri fra kraniet hos psykiatriske patienter i Danmark

I dag er det en gave til videnskaben. Få den fascinerende fortælling om Danmarks hjernesamling, der har 75-årsjubilæum i år.



2024-02-22

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Working Group Website

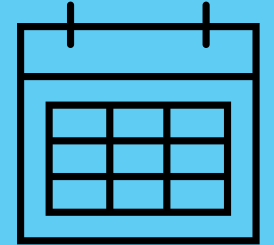
<https://ncrr-adwg.github.io/>

- Slides
- Linked journal articles
- Additional resources: Movies, podcasts, books, etc.

Share with colleagues at other institutions!



Next meeting:
○ 21st of March



Thanks!

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Jette Steinbach

Line Bager

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🐦 @asmhall

References & further resources

- <https://rebeccaskloot.com/the-immortal-life/about-the-book/>
- <https://rebeccaskloot.com/the-immortal-life/henrietta-lacks-foundation/>
- <http://henrietalacksfoundation.org/>
- <https://www.hopkinsmedicine.org/henrietta-lacks/upholding-the-highest-bioethical-standards>
- Laura M. Beskow , *Lessons from HeLa Cells: The Ethics and Policy of Biospecimens*, Annual Review of Genomics and Human Genetics, Aug 2016, <https://doi.org/10.1146/annurev-genom-083115-022536>
- <https://babel.hathitrust.org/cgi/pt?id=ien.35558000331047&seq=185>
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