Welcome

Science Update: The Enduring Legacy of Henrietta Lacks

Presented by:
Dr. Carrie D. Wolinetz

September 16, 2020
7:00 PM ET

Promoting excellence and innovation in science teaching and learning for all

nsta
National Science Teaching Association

Meet today's presenter…

Dr. Carrie D. Wolinetz
National Institutes of Health

NSTA Science Update – September 16th, 2020

The Enduring Legacy of Henrietta Lacks

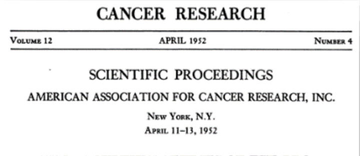
Carrie D. Wolinetz, PhD
Associate Director for Science Policy and
Acting Chief of Staff to the NIH Director

DEPARTMENT OF HEALTH & HUMAN SERVICES · USA


HOLY BIBLE

HeLa Cells and the Lacks Family

- ***1951:*** Biopsy from **He**nrietta **La**cks, 31-year-old patient with aggressive cervical cancer; died 8 months later
    - Cells soon found to be "immortal" – invaluable to research
    - Named **HeLa** – used without Lacks' knowledge, consent



CANCER RESEARCH

VOLUME 12 APRIL 1952 NUMBER 4

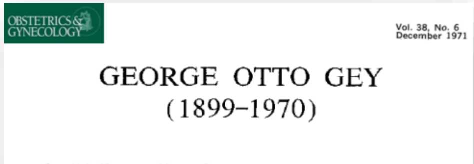
SCIENTIFIC PROCEEDINGS

AMERICAN ASSOCIATION FOR CANCER RESEARCH, INC.

NEW YORK, N.Y.
APRIL 11–13, 1952

TISSUE CULTURE STUDIES OF THE PROLIFERATIVE CAPACITY OF CERVICAL CARCINOMA AND NORMAL EPITHE-

- ***1971:*** Henrietta's identity made public
    - Start of challenges for the Lacks family



OBSTETRICS & GYNECOLOGY

Vol. 38, No. 6
December 1971

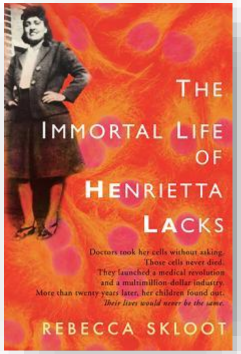
GEORGE OTTO GEY
(1899–1970)

The HeLa Cell and a Reappraisal of its Origin

(1899–1970)

Fig 2. Henrietta Lacks (HeLa)

- ***2010:*** Rebecca Skloot's book brought wide attention to Henrietta, Lacks family, HeLa cells



THE IMMORTAL LIFE OF HENRIETTA LACKS

Doctors took her cells without asking.
Those cells never died.
They launched a medical revolution
and a multimillion-dollar industry.
More than twenty years later, her children found out.
Their lives would never be the same.

REBECCA SKLOOT

HeLa Whole Genome Sequence Made Public (2013)

- ***March 2013:*** German researchers post HeLa genome sequence

The New York Times

SundayReview | The Opinion Pages

OPINION

The Immortal Life of Henrietta Lacks, the Sequel

By REBECCA SKLOOT

Published: March 23, 2013 | 125 Comments

LAST week, scientists sequenced the genome of cells taken without consent from a woman named Henrietta Lacks. She was a black tobacco farmer and mother of five, and though she died in 1951, her cells, code-named HeLa, live on. They were used to help develop our most important vaccines and cancer medications, in vitro fertilization, gene mapping, cloning. Now they may finally help create laws to protect her family's privacy — and yours.

nature International weekly journal of science

NATURE | NEWS

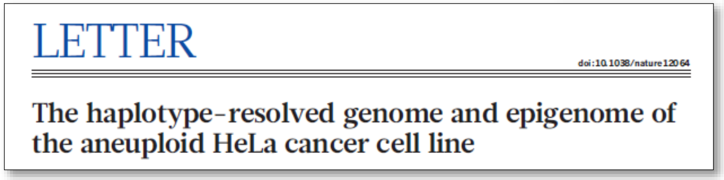
Most popular human cell in science gets sequenced

nature International weekly journal of science

NATURE | NEWS

HeLa publication brews bioethical storm

Genome of controversial cell line no longer public, but another sequence is in the works.



LETTER

doi:10.1038/nature12064

The haplotype-resolved genome and epigenome of the aneuploid HeLa cancer cell line

- ***April–July 2013:*** NIH, Lacks family craft long-term solution

NIH-Lacks Family Agreement: Announced Aug. 7, 2013

The New York Times

A Family Consents to a Medical Gift, 62 Years Later

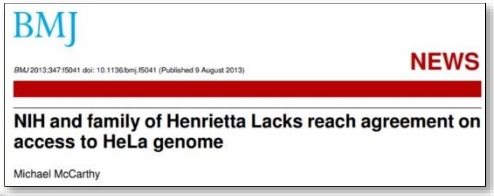
By CARL ZIMMER August 7, 2013

Jeri Lacks Whye, center, one of Henrietta Lacks's grandchildren, with her own daughters, Jabrea, left, and Aiyana Rogers. Monica Lopossay for The New York Times

USA TODAY

NIH makes privacy agreement with Henrietta Lacks' family

Dan Vergano, USA TODAY Published 1:38 p.m. ET Aug. 7, 2013 | Updated 6:22 p.m. ET Aug. 7, 2013



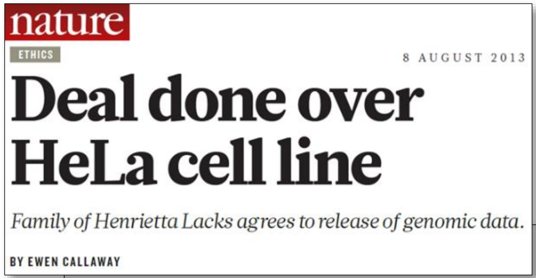
BMJ

NEWS

BMJ 2013;347:f5041 doi: 10.1136/bmj.f5041 (Published 9 August 2013)

NIH and family of Henrietta Lacks reach agreement on access to HeLa genome

Michael McCarthy



nature

ETHICS

8 AUGUST 2013

Deal done over HeLa cell line

Family of Henrietta Lacks agrees to release of genomic data.

BY EWEN CALLAWAY

COMMENT

ENVIRONMENT A road map for reducing China's emissions p.143

EVOLUTION Why do we enjoy the misfortunes of others? p.147

DEVELOPMENT Calestous Juma weighs up a call for a revolution to end hunger p.148

INFLUENZA Plan announced for gain-of-function studies on H7N9 virus p.150

COURTESY OF LACKS FAMILY

Henrietta Lacks' family gather around a historical marker dedicated to her in Virginia in 2011.

Family matters

Kathy L. Hudson and **Francis S. Collins** discuss how and why the US National Institutes of Health worked with the family of Henrietta Lacks, the unwitting source of the HeLa cell line, to craft an agreement for access to HeLa genome data.

shots HEALTH NEWS FROM NPR

PUBLIC HEALTH

Decades After Henrietta Lacks' Death, Family Gets A Say On Her Cells

August 7, 2013 · 1:40 PM ET

Morning Edition talks with NIH's Dr. Francis Collins

NBC NEWS

NIH finally makes good with Henrietta Lacks' family – and it's about time, ethicist says

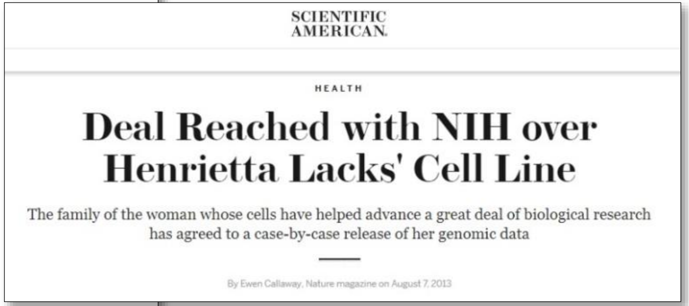
by ART CAPLAN, PH.D.

Cells taken from Henrietta Lacks, shown in the 1940s, eventually helped lead to a multitude of medical treatments. But neither she nor her family gave consent.

The Washington Post

Health & Science

NIH, family of Henrietta Lacks reach deal on access to DNA code



SCIENTIFIC AMERICAN

HEALTH

Deal Reached with NIH over Henrietta Lacks' Cell Line

The family of the woman whose cells have helped advance a great deal of biological research has agreed to a case-by-case release of her genomic data

By Ewen Callaway, Nature magazine on August 7, 2013

The main goal was science and being part of the conversation.

David Lacks Jr.

NIH-Lacks Family Agreement – Details

HeLa Whole Genome Sequence in NIH Database of Genotypes and Phenotypes (dbGaP)

dbGaP
GENOTYPES and PHENOTYPES

- Researchers apply for access
  - Using data only for health, medical, or biomedical research objectives
  - No studies of population origins or ancestry

- Working Group of the NIH Advisory Committee to the Director evaluates all requests

HeLa Genome Data Access Working Group

Carrie D. Wolinetz, Ph.D. (Co-Chair)
Acting Chief of Staff and Associate Director for Science Policy, Office of the Director – *NIH*

Spero Manson, Ph.D. (Co-Chair)
Distinguished Professor of Public Health and Psychiatry and Director, Centers for American Indian and Alaska Native Health; Colorado Trust Chair in American Indian Health, Associate Dean for Research
Colorado School of Public Health

Russ B. Altman, M.D., Ph.D.
Professor, Bioengineering, Genetics, and Medicine and Director, Biomedical Informatics Training Program
Stanford

Ruth Faden, PhD., M.P.H.
Philip Franklin Wagley Professor in Biomedical Ethics and Director, Johns Hopkins Berman Institute of Bioethics Bloomberg School of Public Health
Johns Hopkins University

★ **David Lacks, Jr.**
Representative, Henrietta Lacks Family

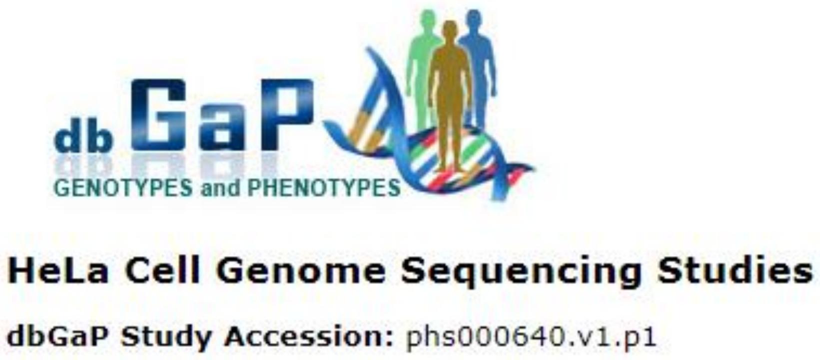
★ **Jeri Lacks-Whye**
Representative, Henrietta Lacks Family

Richard M. Myers, Ph.D.
President, Director and Faculty Investigator
HudsonAlpha Institute for Biotechnology

★ **Veronica Spencer**
Representative, Henrietta Lacks Family

Requests to Access HeLa Genomic Data: 2013-Present

- 89 evaluated and 83 approved
- 19 countries have requested access to data
- Approved uses, outcomes (e.g., publications, IP) publicly available
- Rejections for incomplete applications; unwillingness to share data



HeLa Cell Genome Sequencing Studies

dbGaP Study Accession: phs000640.v1.p1

HeLa Cells in Science and Medicine

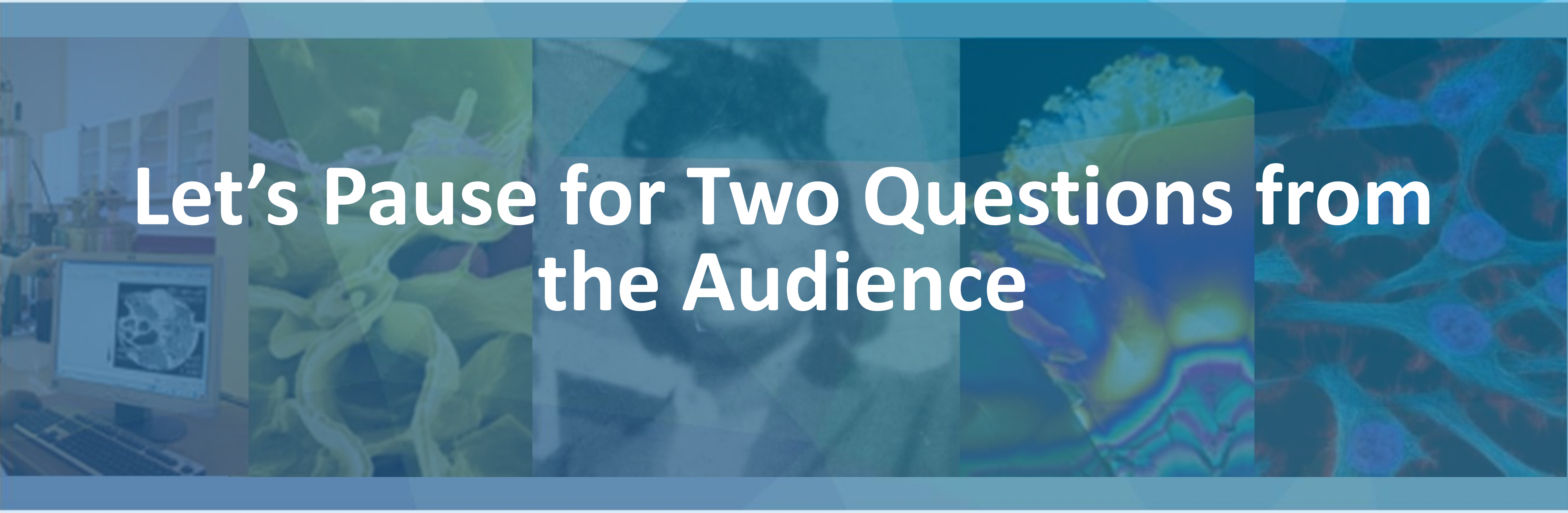
A Google search for "HeLa cells" generates **34.9 million results**

Over **110,000 publications** citing HeLa cells between 1953 to 2018

In the last ten years, the majority of **Nobel Prizes** in medicine have used HeLa cells

HeLa cells accompanied the first human into **space** in 1961

Critical discoveries related to **COVID** vaccine development research



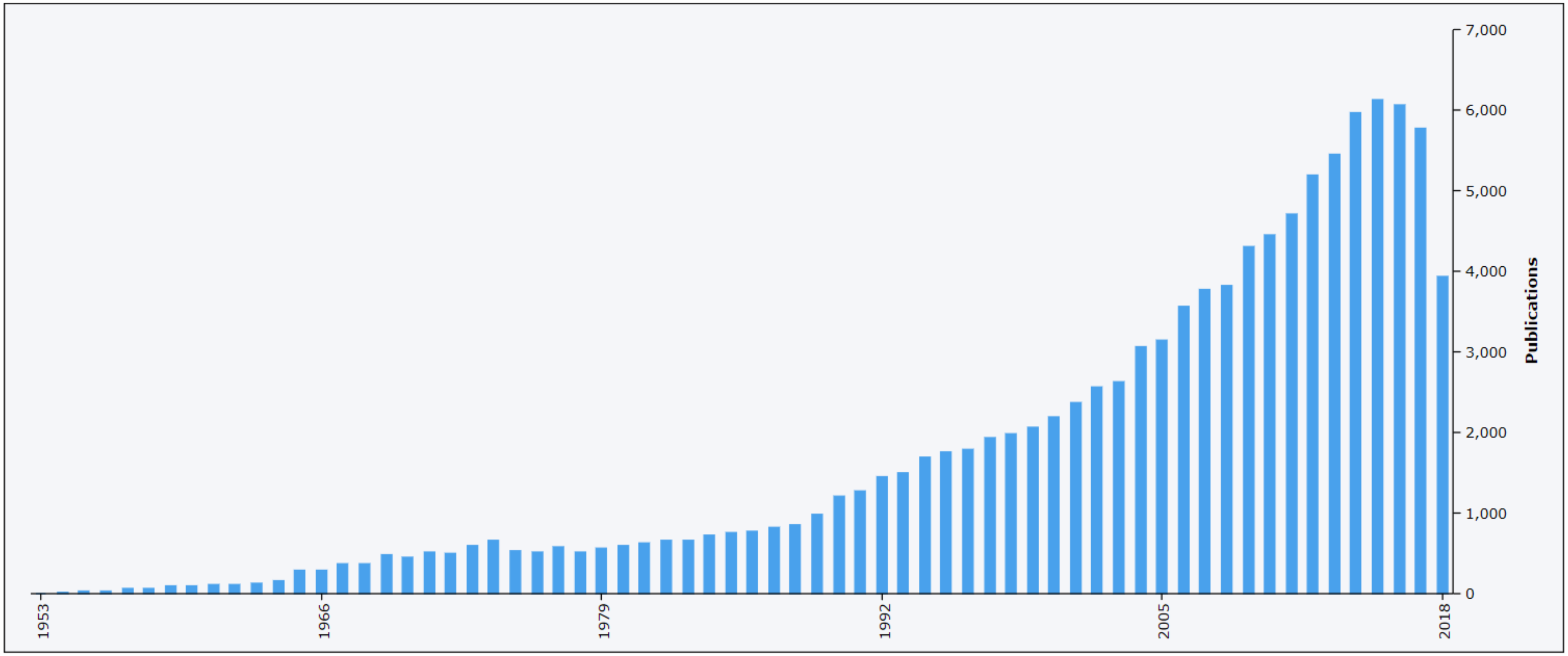
Let’s Pause for Two Questions from the Audience

The Contribution of HeLa Cells to Biomedical Research

Over 100,000 publications resulting from research using HeLa Cells

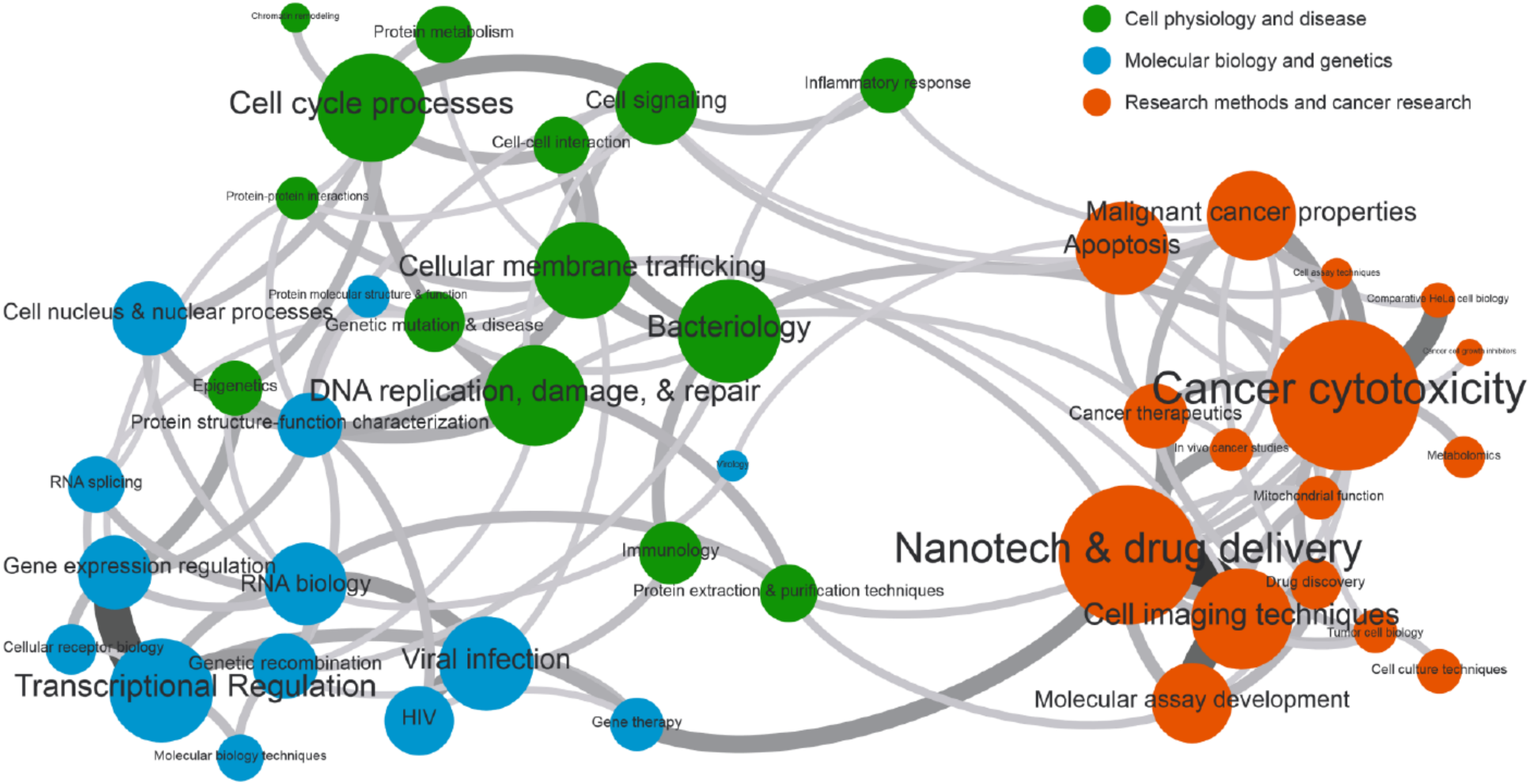
- 142$^+$ countries
- 3 Nobel Prizes (telomerase, HPV & cancer, and nanoscale imaging)

Number of publications, per year, from 1953 to 2018



*Publications are still being populated for the years 2016, 2017, and 2018 and the number of publications using HeLa cells per year are lower as a result.

Topics of HeLa Cell Research



Credit: NIH Library on behalf of the HeLa Genome Data Access Working Group

The National Institutes of Health (NIH)

United States Steward of Medical and Behavioral Research

“Science in pursuit of **fundamental knowledge** about the nature and behavior of living systems… and the **application of that knowledge** to extend healthy life and reduce illness and disability”

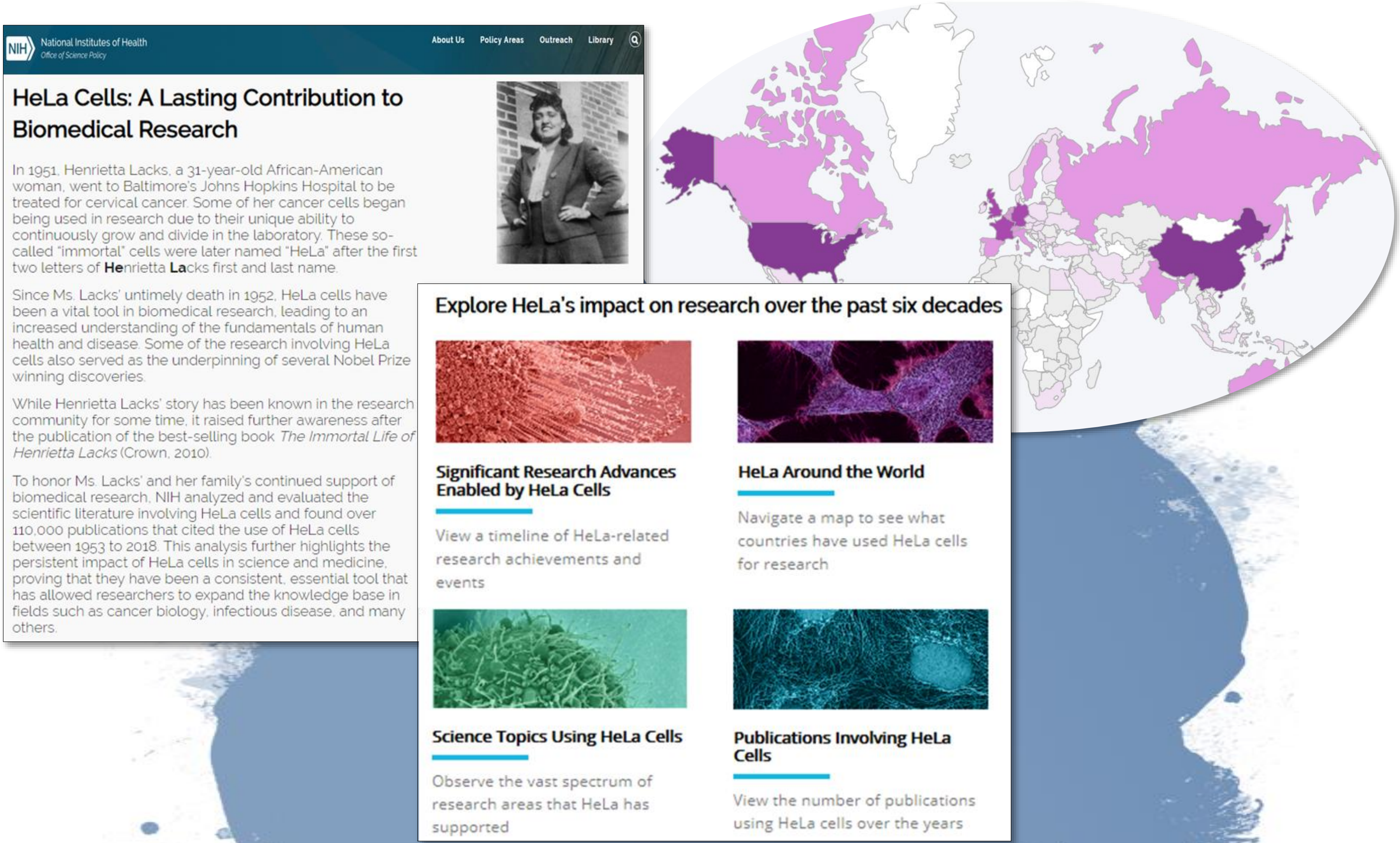
Getting the Word Out

- Given a Voice: An Update on the NIH-Lacks Family Partnership

- Annual Biomedical Research Conference for Minority Students (ABRCMS)

Reaching a Broader Community

https://osp.od.nih.gov/scientific-sharing/hela-cells-landing/



HeLa Cells: A Lasting Contribution to Biomedical Research

In 1951, Henrietta Lacks, a 31-year-old African-American woman, went to Baltimore's Johns Hopkins Hospital to be treated for cervical cancer. Some of her cancer cells began being used in research due to their unique ability to continuously grow and divide in the laboratory. These so-called "immortal" cells were later named "HeLa" after the first two letters of **He**nrietta **La**cks first and last name.

Since Ms. Lacks' untimely death in 1952, HeLa cells have been a vital tool in biomedical research, leading to an increased understanding of the fundamentals of human health and disease. Some of the research involving HeLa cells also served as the underpinning of several Nobel Prize winning discoveries.

While Henrietta Lacks' story has been known in the research community for some time, it raised further awareness after the publication of the best-selling book *The Immortal Life of Henrietta Lacks* (Crown, 2010).

To honor Ms. Lacks' and her family's continued support of biomedical research, NIH analyzed and evaluated the scientific literature involving HeLa cells and found over 110,000 publications that cited the use of HeLa cells between 1953 to 2018. This analysis further highlights the persistent impact of HeLa cells in science and medicine, proving that they have been a consistent, essential tool that has allowed researchers to expand the knowledge base in fields such as cancer biology, infectious disease, and many others.

Explore HeLa's impact on research over the past six decades

Significant Research Advances Enabled by HeLa Cells

View a timeline of HeLa-related research achievements and events

HeLa Around the World

Navigate a map to see what countries have used HeLa cells for research

Science Topics Using HeLa Cells

Observe the vast spectrum of research areas that HeLa has supported

Publications Involving HeLa Cells

View the number of publications using HeLa cells over the years

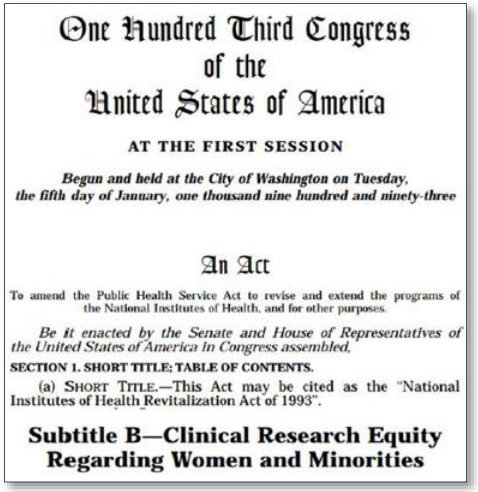
Let’s Pause for Two Questions from the Audience

Participants as Partners: Walking the Talk

- Moving away from one-way relationships with human “subjects”
- True meaning of engagement
- Community and participant partnerships in research are essential and becoming more common
    - E.g., *All of Us* – based on patient engagement, trust, and respect
    - Understanding Tribal or underrepresented community perspectives on research and data sharing

Turning Discovery into Health

Enhancing Diversity Among Clinical Research Participants



One Hundred Third Congress
of the
United States of America

AT THE FIRST SESSION

Begun and held at the City of Washington on Tuesday,
the fifth day of January, one thousand nine hundred and ninety-three

An Act

To amend the Public Health Service Act to revise and extend the programs of the National Institutes of Health, and for other purposes.

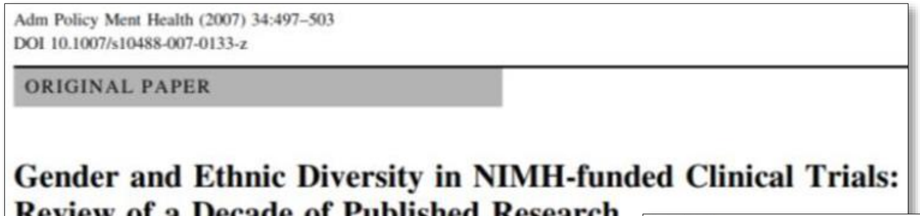
Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

(a) SHORT TITLE.—This Act may be cited as the "National Institutes of Health Revitalization Act of 1993".

Subtitle B—Clinical Research Equity Regarding Women and Minorities

---



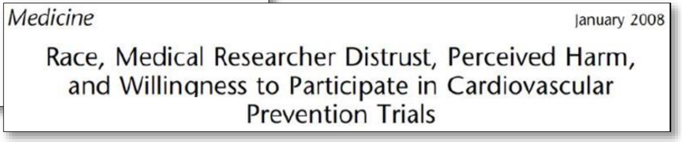
Adm Policy Ment Health (2007) 34:497–503
DOI 10.1007/s10488-007-0133-z

ORIGINAL PAPER

Gender and Ethnic Diversity in NIMH-funded Clinical Trials: Review of a Decade of Published Research

Winnie W. S. Mak · Rita W. Law · Jennifer Alvidrez · Eliseo J. Pérez-Stable

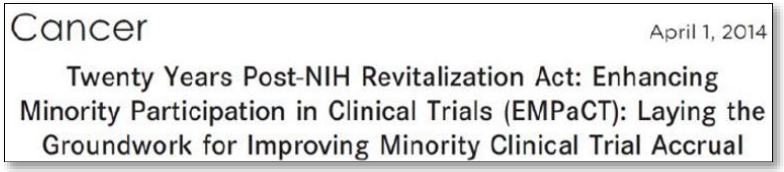
---



Medicine January 2008

Race, Medical Researcher Distrust, Perceived Harm, and Willingness to Participate in Cardiovascular Prevention Trials

---



Cancer April 1, 2014

Twenty Years Post-NIH Revitalization Act: Enhancing Minority Participation in Clinical Trials (EMPaCT): Laying the Groundwork for Improving Minority Clinical Trial Accrual

---

American Journal of
RESPIRATORY AND CRITICAL CARE MEDICINE®

March 1 2015

Moving toward *True* Inclusion of Racial/Ethnic Minorities in Federally Funded Studies

A Key Step for Achieving Respiratory Health Equality in the United States

---

nature

18 SEPTEMBER 2014

Missing patients

Effective clinical studies must consider all ethnicities — exclusion can endanger populations, says **Esteban G. Burchard**.

PLOS | MEDICINE

POLICY FORUM

December 15, 2015

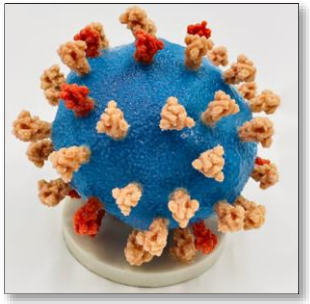
Diversity in Clinical and Biomedical Research: A Promise Yet to Be Fulfilled

Sam S. Oh[1], Joshua Galanter[1,2], Neeta Thakur[1], Maria Pino-Yanes[1,3,4], Nicolas E. Barcelo[1], Marquitta J. White[1], Danielle M. de Bruin[1], Ruth M. Greenblatt[1,5], Kirsten Bibbins-Domingo[1,6], Alan H. B. Wu[7], Luisa N. Borrell[8], Chris Gunter[9,10], Neil R. Powe[1,6], Esteban G. Burchard[1,2]*

Present-Day | COVID-19 & Disparities

Enhancing Diversity in COVID Therapeutics & Vaccine Research

- **Disproportionate effects** of COVID on communities of color, other vulnerable populations



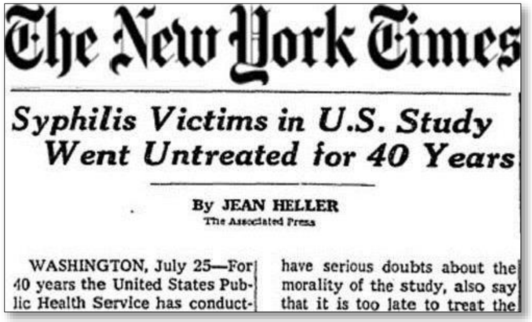
- **Priorities** to address disparities include**:**
  - Inclusion of communities of color in clinical trials
  - Population-specific efforts to reduce health disparities
- **Thinking through diversity** for vaccine distribution:
  - National Academies report, "*A Framework for Equitable Allocation of Vaccine for the Novel Coronavirus*"

The National Academies of SCIENCES ENGINEERING MEDICINE

Biomedical Research and Participant Diversity

Ongoing Challenge; Many Causes…

- **Legacy of Tuskegee** casts a long shadow
- **1932:** US Public Health Service recruited “colored people” with “bad blood”
  - No mention of syphilis – no informed consent
- **1945-47:** new drug, Penicillin, now standard treatment
  - *Never* offered to participants
- **1972:** article exposes study; study ends
  - 1974: $10M out-of-court settlement reached
- **1997:** President Bill Clinton offers formal apology on behalf of US



The New York Times

Syphilis Victims in U.S. Study Went Untreated for 40 Years

By JEAN HELLER
The Associated Press

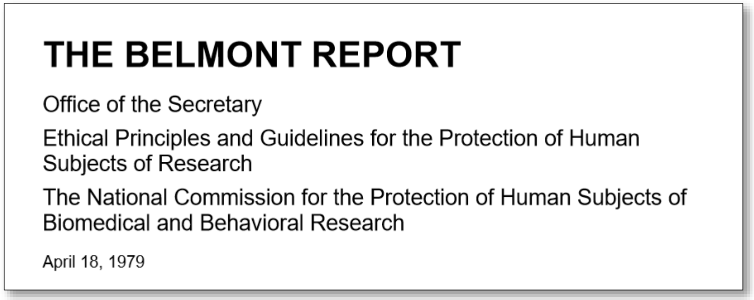
WASHINGTON, July 25—For 40 years the United States Public Health Service has conduct-

have serious doubts about the morality of the study, also say that it is too late to treat the

Evolving System of Human Participant Protections

Troubling Histories, Direct Impacts on Change

- **1979:** Belmont Report
  - Ethical Principles and Guidelines for the Protection of Human Subjects



THE BELMONT REPORT

Office of the Secretary

Ethical Principles and Guidelines for the Protection of Human Subjects of Research

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research

April 18, 1979

- **1981:** Common Rule
  - Ethics of US behavioral & biomedical research involving humans
    - Research institution review, compliance
    - Protections for vulnerable research subjects

Working With the Lacks Family to Broaden Our Understanding of “Research Participants”

- U. of Illinois Cancer Center event: Advancing Trust in Medical Research
- NIH-supported researcher Dr. Robert Winn engaged four generations of Lacks family, >500 community members, to discuss
  - How to increase diversity among participants in clinical trials
  - How historical mistrust affects **precision health**

The *All of Us* Research Program

Description: a historic, longitudinal effort to gather data from one million or more people living in the US … that takes into account individual differences in lifestyle, socioeconomics, environment, and biology

Mission: accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care – for all of us

All of Us: Objectives

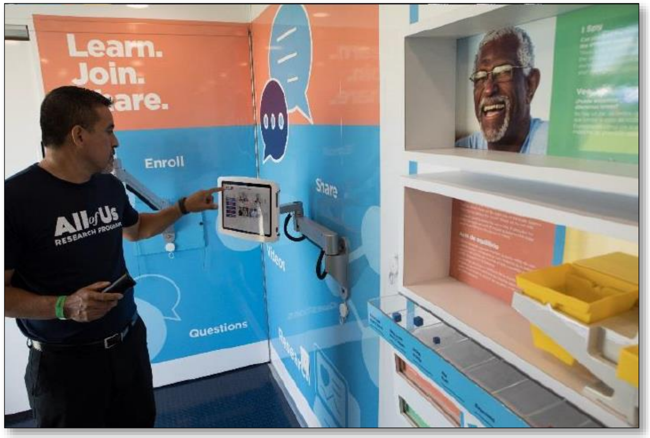
- Nurture enduring relationships with participant partners
  - Who reflect the nation’s diversity – across ages, races/ethnicities, genders, geographies, backgrounds…
- Build richest, largest-ever biomedical resource
  - Dataset that’s as easy, safe, and free to access as possible
- Catalyze a robust biomedical research ecosystem
  - Engaging a wide array of researchers, funders

Earning Participants' Trust

STAT

To advance medicine's future, the NIH tries to win the trust of communities mistreated in the past

By LEV FACHER @levfacher / SEPTEMBER 22, 2017 Reprints



Sign up at Joinallofus.org

I realized that *All of Us* was about my family's story.
It was about your family's story.
It's about what we face every day.

Veronica Robinson
All of Us Launch, Chicago
May 6, 2018

Recent Focus – *Remembering the Legacy*

VIEWPOINT

Recognition of Research Participants' Need for Autonomy
Remembering the Legacy of Henrietta Lacks

Carrie D. Wolinetz, PhD
National Institutes of Health, Bethesda, Maryland.

Francis S. Collins, MD, PhD
National Institutes of Health, Bethesda, Maryland.

August 1, 2020, marked what would have been the 100th birthday of Henrietta Lacks, the Black woman whose cervical cancer cells gave rise to the immortal HeLa cell line. HeLa cells have played an extraordinary role in scientific research, underlying multiple Nobel Prize–winning discoveries and enabling medical advances for polio, cancer, Ebola virus disease, sickle cell disease, and countless other conditions.

However, the bright biomedical legacy of HeLa cells is tarnished by the injustice of this biospecimen being preserved without the consent of Lacks or her family, whose identity was revealed decades ago.[1] This failure, while permitted by the ethical norms of the time, has affected the Lacks family in profound ways, including limiting the comfort, pride, and satisfaction that comes with knowing a deceased loved one made an important contribution to science. Today's current events provide an opportune time to reflect on the experiences of Lacks and other African Americans in the context of biomedical research, and to look ahead to what can be done to make that future far more just and equitable.

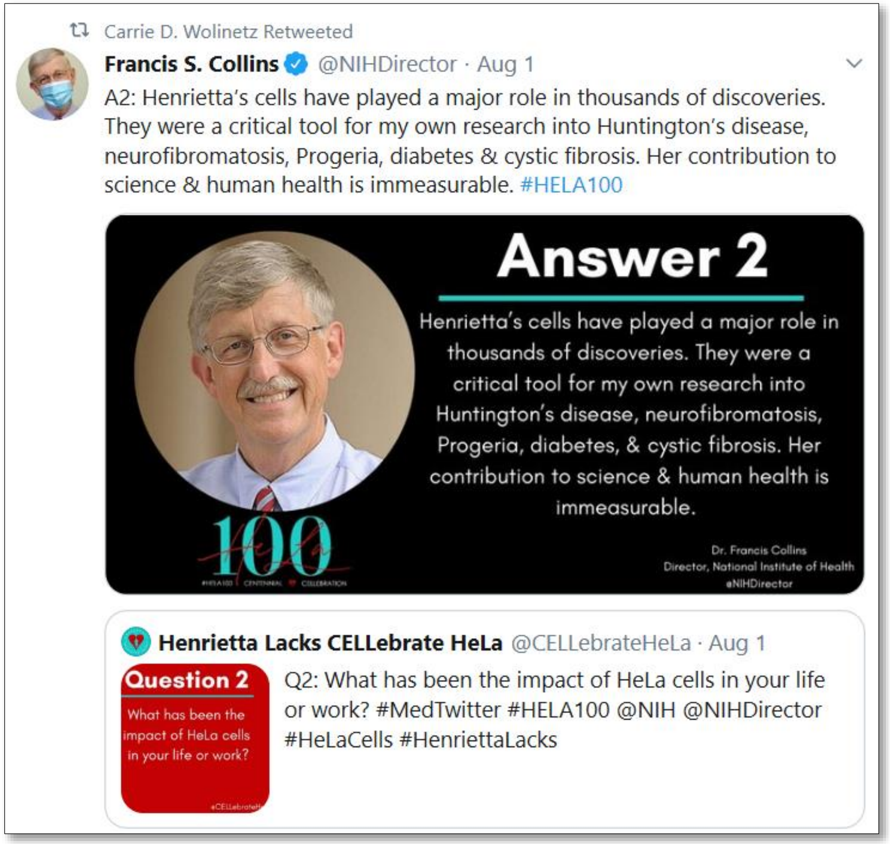
In the wake of the killing of George Floyd and other similar events, the US may have reached an inflection point in challenging systemic racism and a long history of injustices against Black individuals. The research disproportionately affected Black persons and many other people of color, with Black people experiencing a mortality rate 2 to 3 times as high as White or Asian American individuals.[5-7]

Scientific and community leaders have begun to emphasize the need to recruit a diverse pool of participants for COVID-19 vaccine trials, even as antivaccination interests attempt to build on the history of mistrust in the Black community to discourage research participation and increase vaccine hesitancy.[8] In an ironic twist of fate, early work that characterized human angiotensin-converting enzyme 2 (ACE2) as a receptor for SARS-CoV-2 and described the mechanism for entry (which formed the basis for targets for leading vaccine candidates) used HeLa cells,[9] thus creating a surreal circumstance in which the research and medical communities are asking Black people to have trust in vaccines developed using cells obtained from a Black woman without consent.

What may not be realized about the cautionary tale of HeLa cells, however, is that something quite similar could still happen today. The current system for protecting human research participants does not require consent for deidentified biospecimens obtained from clinical practice—just like Lacks' tumor—to be used in medical research. As the US reflects on the progress that biomedical research has made and, hopefully, how the concepts of equality, ethics, and fairness have evolved in the 100 years since Lacks' birth, perhaps the moment has finally arrived to think about how to rectify the situation regarding biospecimen consent. The time is overdue for the scientific community in the

> A genuine culture of respect for research participants demands that they be asked to agree to use of their biospecimens, regardless of identifiability.

Recent Focus – *Remembering the Legacy*



Carrie D. Wolinetz Retweeted

Francis S. Collins @NIHDirector · Aug 1

A2: Henrietta's cells have played a major role in thousands of discoveries. They were a critical tool for my own research into Huntington's disease, neurofibromatosis, Progeria, diabetes & cystic fibrosis. Her contribution to science & human health is immeasurable. #HELA100

Answer 2

Henrietta's cells have played a major role in thousands of discoveries. They were a critical tool for my own research into Huntington's disease, neurofibromatosis, Progeria, diabetes, & cystic fibrosis. Her contribution to science & human health is immeasurable.

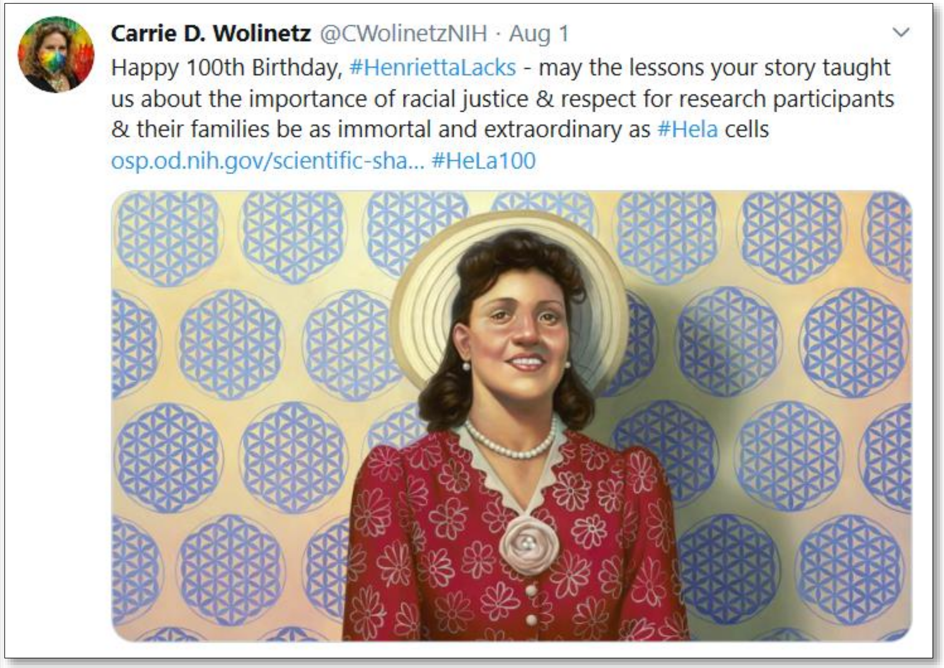
Dr. Francis Collins
Director, National Institute of Health
@NIHDirector

Henrietta Lacks CELLebrate HeLa @CELLebrateHeLa · Aug 1

Question 2

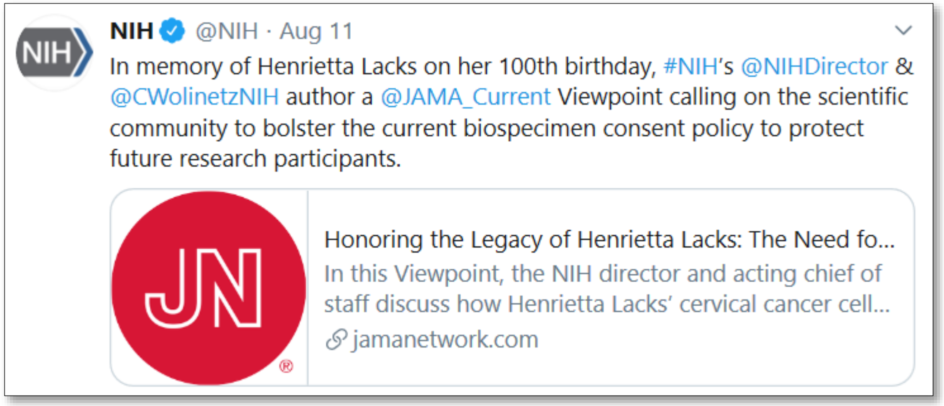
What has been the impact of HeLa cells in your life or work?

Q2: What has been the impact of HeLa cells in your life or work? #MedTwitter #HELA100 @NIH @NIHDirector #HeLaCells #HenriettaLacks



Carrie D. Wolinetz @CWolinetzNIH · Aug 1

Happy 100th Birthday, #HenriettaLacks - may the lessons your story taught us about the importance of racial justice & respect for research participants & their families be as immortal and extraordinary as #Hela cells osp.od.nih.gov/scientific-sha... #HeLa100



NIH @NIH · Aug 11

In memory of Henrietta Lacks on her 100th birthday, #NIH's @NIHDirector & @CWolinetzNIH author a @JAMA_Current Viewpoint calling on the scientific community to bolster the current biospecimen consent policy to protect future research participants.

Honoring the Legacy of Henrietta Lacks: The Need fo...

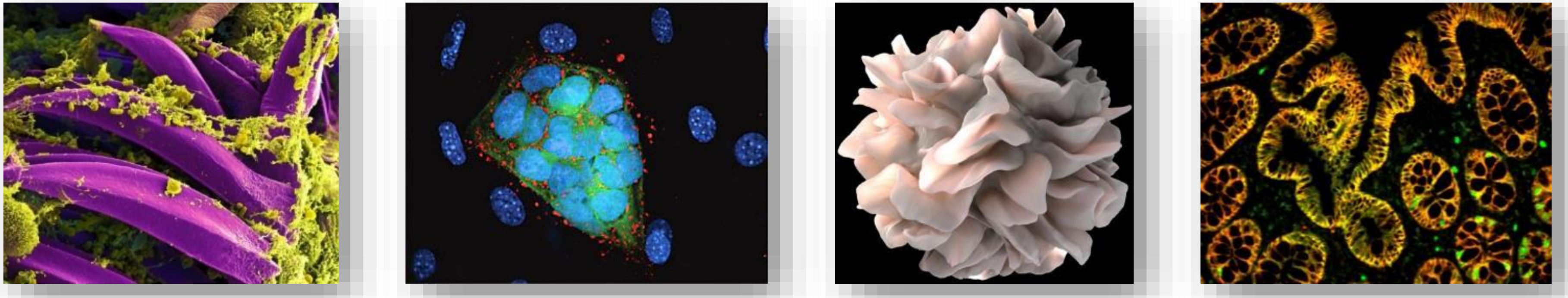
In this Viewpoint, the NIH director and acting chief of staff discuss how Henrietta Lacks' cervical cancer cell...

jamanetwork.com

NIH…*Turning Discovery Into Health*

www.nih.gov/hope

@CWolinetzNIH



Additional Questions

(as time allows)

Thanks to Today's Presenter…

Dr. Carrie D. Wolinetz
National Institutes of Health

Thank you for participating!

Collection of Resources

This collection includes the slides (as PDF), handouts and other resources.

Link to the collection:

https://my.nsta.org/collection/tqUPUX8Uclg_E

NSTA Web Seminars (free)

Science Update: Countdown to ISS 20
October 15, 7:00 PM ET

Web Seminar: Developing a Competitive Application for Shell Teaching Awards
October 29, 7:00 PM ET

https://my.nsta.org/webseminars

nsta

NSTA Member Web Seminars

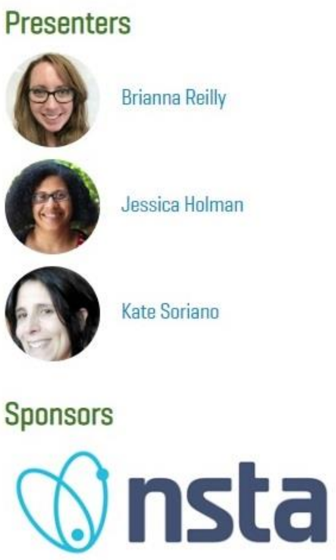
Transforming Science Learning: Phenomena Drive Instruction: How to Choose and Use Phenomena When Designing Instruction

September 23, 7:00 PM ET

https://my.nsta.org/webseminars

NSTA Web Seminar Series *(October)*

NSTA Web Seminar Series: Topic Study for K-12 Science Teachers: Distance-Learning Strategies that Support Student Sensemaking



Presenters

Brianna Reilly

Jessica Holman

Kate Soriano

Sponsors

nsta

October 1, 8, 15, 22
7:00 – 8:30 PM ET

Registration:
NSTA member: $60
Associate member/Non-member: $75
Group rate (25 individuals): $1,500

https://my.nsta.org/wssoct20

Thanks to the NSTA Virtual Learning Team

National Science Teaching Association
Tricia Shelton, Director Professional Learning
Flavio Mendez, Assistant Executive Director
Kate Soriano, Standards Implementation Specialist
Wendy Binder, Program Director
Laura Jackson, Project Manager
Eddie Hausknecht, Web Developer
Don Boonstra, Technical Coordinator

This concludes today's program.

nsta