

NATIONAL INSTITUTES OF HEALTH

HELA GENOME DATA ACCESS

WORKING GROUP REPORT FINDINGS TO THE ACD



Garth Graham, MD, MPH & Lyric Jorgenson, PhD
HeLa Working Group Co-Chairs

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REMINDER

THE HELA GENOME DATA USE AGREEMENT

Researchers are expected to:

- Apply for HeLa whole genome sequence access through dbGaP & ACD review
- Abide by HeLa Genome Data Use Agreement terms, including:
 - Using data only for biomedical research purposes
 - Disclosing whether the research could result in a patent or commercial product/service
 - Respecting the privacy of the family by safeguarding the data and not attempting to contact them
 - Recognizing the contributions of Henrietta Lacks and her family by including an acknowledgment in publications and presentations
- Deposit future whole genome sequence data into dbGaP

REMINDER

HELA GENOME DATA ACCESS WORKING GROUP ROSTER

- **Garth Graham, MD, MPH (Co-Chair)**
Google/YouTube
- **Lyric Jorgenson, PhD (Co-Chair)**
National Institutes of Health
- **Russ Altman, MD, PhD**
Stanford University
- **Ruth Faden, PhD, MPH**
Johns Hopkins University
- **David Lacks, Jr.**
Representative, Henrietta Lacks Family
- **Jeri Lacks-Whye**
Representative, Henrietta Lacks Family
- **Richard Myers, PhD**
HudsonAlpha Institute for Biotechnology
- **Veronica Robinson**
Representative, Henrietta Lacks Family
- **Cheryl Jacobs, PhD (Executive Secretary)**
National Institutes of Health

REMINDER

ACCESS REQUEST EVALUATION CRITERIA

- **Is the proposed research focused on health, medical, or biomedical research objectives?**
 - Is the proposed research related to determining the ancestry or population origins of HeLa cells?
- **Are there any plans to develop intellectual property? Specifically:**
 - Does the requestor anticipate or foresee IP or developing commercial products or services from the proposed research?
 - Has the requestor agreed to notify NIH if their plans for IP or commercial products change?
- **Are there any plans to publish or present findings?**

UPDATE

SUBMITTED ACCESS REQUESTS

# Requests	Status/Outcome
98 (total)	Evaluated by the HeLa Genome Data Access Working Group
91	Approved by NIH Director
1	Disapproved by NIH Director
5	Rejected for insufficiency by NIH staff (i.e., requestors did not respond to requests for clarifications regarding publication plans, IP, and/or the non-technical summary)
1	To be reported to ACD today

UPDATE

CURRENT REQUEST: WG ASSESSMENT

Project Title	Requestor's Affiliation	Project Summary	Working Group Assessment
Re-analysis of engineered L1 retrotransposition in cultured HeLa cells	University Of Queensland, Australia	<ul style="list-style-type: none">• A prior study (Flasch et al., Cell, 2019) used HeLa cells to generate HeLa cell whole genome sequence data to study jumping gene preference. They submitted their HeLa cell data to the HeLa Cell Genome Sequencing Studies as a part of the NIH-Lacks Family Agreement.• The requestor is seeking access to HeLa cell data submitted by Flasch et al. to see if they are able to repeat the research results.• No plans to develop a commercial product or service or to file IP but will notify NIH if their plans change	CONSISTENT WITH DATA USE AGREEMENT

UPDATE

CURRENT REQUEST: WG ASSESSMENT **ACD VOTE**

Project Title	Requestor's Affiliation	Project Summary	Working Group Assessment
Re-analysis of engineered L1 retrotransposition in cultured HeLa cells	University Of Queensland, Australia	<ul style="list-style-type: none">• A prior study (Flasch et al., Cell, 2019) used HeLa cells to generate HeLa cell whole genome sequence data to study jumping gene preference. They submitted their HeLa cell data to the HeLa Cell Genome Sequencing Studies as a part of the NIH-Lacks Family Agreement.• The requestor is seeking access to HeLa cell data submitted by Flasch et al. to see if they are able to repeat the research results.• No plans to develop a commercial product or service or to file IP but will notify NIH if their plans change	CONSISTENT WITH DATA USE AGREEMENT