Summary of the NIH HeLa Genome Data Use Agreement

The National Institutes of Health (NIH) has established a special process for making HeLa cell sequence data available for biomedical research. NIH-funded researchers who sequence HeLa cell lines will be expected to deposit their data into NIH's database of Genotypes and Phenotypes (dbGaP) and requests for access to the data will be subject to a special review and approval process involving the HeLa Genome Data Access Working Group of the Advisory Committee to the Director (ACD). [1]

The HeLa Genome Data Use Agreement outlines terms and conditions for the use of HeLa genome data. The Working Group will review requests for (DAR) and agree to abide by certain terms of use, including

following:

- To use the data for the approved use only.
- To disclose whether the research is intended or could be reasonably expected to result in a patent or commercial product or service and, if so, a description of that patent or commercial product or service.
- To agree to the posting of their name and information about how they plan to use the data on NIH data repository websites.
- To respect the privacy of the family members of Henrietta Lacks by not attempting to contact them.
- To safeguard the HeLa genome data by not sharing them with unapproved users, by following data security measures and by reporting any data security breaches or unapproved use of the data to NIH.
- To recognize the contribution of Henrietta Lacks and her surviving family members to the advancement of biomedical research by including an acknowledgement which is provided in the Agreement, when reporting or presenting scientific findings based on the HeLa genome data.
- To provide yearly research progress updates summarizing the progress made during the one year access period, describing any research plans for the next year of access if submitting a renewal application, and reporting all publications, presentations, and intellectual property generated from the use of the data.

NIH may terminate the Agreement and revoke access to all NIH genomic datasets at any time if