HeLa Sequencing and Genomic Privacy: The Next Chapter

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This month's issue of *G3: Genes|Genomes|Genetics* features the article "The Genomic and Transcriptomic Landscape of a HeLa Cell Line" by Landry *et al.*, and presents a genomic resource for the most widely used cell line in research. The early online version of the article was published March 11, 2013, along with the release of underlying sequence data in various public databases, and as supplemental information. Shortly thereafter, because of concerns about genetic privacy posed by the descendants of Henrietta Lacks, from whose tumor the HeLa cell line was derived in 1951, the authors chose to remove the data until the family's questions could be addressed. A resolution was arranged after National Institutions of Health (NIH) Director Dr. Francis Collins, and NIH Deputy Director for Science, Outreach, and Policy, Dr. Kathy L. Hudson, held a series of conversations with the Lacks family resulting in an understanding of how these data could be made available to researchers. The data associated with the article are now available to researchers via the database of Genotypes and Phenotypes (dbGaP), hosted by the the NCBI.

Despite the author's adherence to existing ethical guidelines, after *G3*'s early online publication of the article in March, a debate arose over the way genomic data are handled and accessed, indicating that policy or guideline changes may be warranted. Indeed, such modifications could have a profound impact for scientists and society alike. As a journal that publishes studies of genomic data for the benefit of scientific progress, we at *G3* recognize the importance of broad discussions about the genome sciences involving the general public, policy makers, scientists and health care practitioners.

To that end, we also publish in this month's issue of *G3*, three Perspectives articles written by bioethicists and scientists experienced in the scientific, legal, and ethical aspects of human genomics and medicine. We invited the authors to contribute their articles independently of one another, and prior to the recent resolution to place the Landry *et al.* genome sequence data in dbGaP. Together, these articles engage the reader in the complexities of topics such as genetic privacy, consent, access, public awareness, and the current legal and cultural norms that surround human genomics research. The authors also frame issues about data access from a (recent) historical point of view, including open access databases such as those associated with HapMap and the 1000 Genomes Project, as well as those with controlled access databases such as the International Cancer Genome Consortium. Because the current landscape is varied, we hope to present a broad view.

Timothy Caulfield and Amy L. McGuire ("Policy Uncertainty, Sequencing and Cell Lines"), reflect thoughtfully on current policy ambiguities and the importance of addressing this lack of clarity. They highlight two issues that arose in the public arena in response to publication of this HeLa study: ownership and control of biological specimens, and obligations of genomics researchers to third party relatives.

Bartha M. Knoppers ("From Tissues to Genomes") focuses on the use of patient tissue samples, and the resulting ethical, social, and legal implications.

And Michael J. Szego, Janet A. Buchanan, and Stephen W. Scherer ("Building Trust in 21st Century Genomics") consider some of the lessons offered by sequencing of the HeLa genome. The authors propose for researchers and journal editors a series of questions to help assess whether an ethics review should be considered before proceeding to undertake a study in genomics, and may also help to guide the adaptation of scientific research to handle the onslaught of genomic data in a manner that balances societal concerns about privacy against benefits for scientific progress.

Genomic data has proven extremely useful in understanding the molecular causes of serious diseases and offering new options for treatments. Understanding the function (or dysfunction) of genomes requires knowledge of their sequences. Having reliable genomic sequence data for the most widely used cell line in research sheds new light on this resource, and so the availability of this data to researchers will be valuable. We are glad to have been able to play a role in increasing the potential of these important cells as they continue to catalyze advances in biological and biomedical research.

LITERATURE CITED

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