



**NATIONAL CANCER INSTITUTE**  
**Cancer Moonshot Biobank**

Ethical, Legal and Social Implications (ELSI) Sub-study

Mini-symposium

June 16, 2021

3:00-5:30 PM EST

The Cancer Moonshot<sup>SM</sup> Biobank is a National Cancer Institute (NCI)-sponsored study that aims to accelerate cancer research through the collection of longitudinal biospecimens from cancer patients receiving standard of care therapy. The Biobank study incorporates several approaches to facilitate diverse participant engagement, including return of tumor biomarker test results directly to patients and providers, use of e-consent, local engagement, and an interactive participant and provider website. These interwoven facets of the Biobank provide a special opportunity to conduct Ethical, Legal, and Social Implications (ELSI)-focused research associated with the study.

The Biobank is developing a funding opportunity to support an embedded ELSI research sub-study. The mini-symposium will provide an introduction to the Biobank study, a presentation on ELSI issues related to engaging diverse populations in biobanking, and a presentation of a prior multidimensional ELSI research study embedded in the NIH Genotype-Tissue Expression project (GTEx). A discussion period will be included to invite attendees' ideas about critical ELSI issues that could be investigated within the Biobank study.

The Biobank study is being conducted in partnership with medical institutions that are a part of the NCI Community Oncology Research Program (NCORP). To achieve a truly embedded study, applications to the funding opportunity should include NCORP investigator(s) and may include collaborator(s) outside of NCORP.

Visit us at: [CancerMoonshotBiobank.cancer.gov](https://CancerMoonshotBiobank.cancer.gov)



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Agenda

<b>Cancer Moonshot Biobank Overview and Opportunity for an embedded ELSI sub-study</b> <i>Helen Moore, Ph.D.</i> <i>Branch Chief, NCI Biorepositories and Biospecimen Research Branch (BBRB)</i> <i>Esmeralda Casas-Silva, Ph.D.</i> <i>Scientific Program Manager, NCI BBRB</i>	3:00-3:20 PM
<b>Ethical Considerations for Biobank Donation and Research: Diverse, Underserved Community Concerns</b> <i>Claudia Baquet, M.D, Ph.D., M.P.H.</i> <i>President, Hope Institute, LLC</i>	3:20-4:00 PM
Q&A	4:00-4:10 PM
<b>Incorporating an ELSI Project in a Complex Biomedical National Initiative: the Genotype-Tissue Expression Project (GTEx)</b> <i>Laura Siminoff, Ph.D.</i> <i>Dean, Temple University College of Public Health</i>	4:10-4:50 PM
Q&A	4:50-5:00 PM
<b>ELSI sub-study application</b> <i>Esmeralda Casas-Silva, Ph.D.</i> <i>Scientific Program Manager, NCI BBRB</i>	5:00-5:05 PM
<b>Group discussion</b>	5:05-5:25 PM
<b>Closing</b>	5:25-5:30 PM

## Invited Speakers

### **Claudia Baquet, M.D, Ph.D., M.P.H.**



Dr. Claudia Baquet is a cancer and health disparities researcher and advocate whose research laid a foundation for what is now called “cancer health disparities research and social determinants of health”. Her contributions include her landmark research while at the National Cancer Institute (NCI/NIH) [1984-1992] and her role on the Secretary’s Task Force on Black and Minority Health Chapters on Cancer and Health Services. These led to a policy change at NCI in reporting of cancer statistics by requiring the inclusion of race and ethnic specific data which were essential for development of a research agenda to address cancer rates in African Americans. She contributed to federal policy and description of health needs for populations in the U.S. Insular Areas, undocumented, and rural underserved. She served as Deputy Assistant Secretary for Minority Health in HHS/PHS (1992-1994).

Dr. Baquet received her M.D. from Meharry Medical College, Nashville Tennessee, her Ph.D. from the University of Maryland, and her M.P.H. in epidemiology from Johns Hopkins University, School of Hygiene and Public Health. Her residency was in pathology at St. Louis University and Wadsworth Veterans Administration Hospital. Her cancer risk assessment training was at the City of Hope.

### **Laura Siminoff, Ph.D.**



Dr. Laura Siminoff is the Dean at the College of Public Health and the Laura H. Carnell Professor of Public Health at Temple University. She received her Ph.D. from Johns Hopkins University. Prior to Temple University, Dr. Siminoff held faculty positions of rising responsibility at the University of Pittsburgh, Case Western Reserve University, and Virginia Commonwealth University. Dr. Siminoff has received numerous awards and honors, published over 200 articles and book chapters, and has been awarded over \$43 million dollars in funding from the National Institutes of Health and the Department of Defense among others. She is an internationally recognized leader in health communication, especially in the field of empirical bioethics and qualitative and multi-method research tools. Much of her research has been focused in the areas of cancer and organ and tissue donation for transplantation.

Dr. Siminoff participated in the Genotype-Tissue Expression Project (GTEx) launched in 2010 by the National Institutes of Health. The initiative characterized genetic associations across up to 49 tissues from over 900 postmortem donors. An essential part of the project was the ELSI project led by Dr. Siminoff which studied the best practices for communicating and obtaining consent from donor families.