

Curriculum Vitae

Sara Chandros Hull, PhD
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CURRENT POSITIONS

- 2019-present** **Chair**
NIH Intramural Institutional Review Board
- 2016-present** **Associate Investigator**
NHGRI, NIH
- 2004-present** **Director**
Bioethics Core, Office of the Clinical Director
National Human Genome Research Institute (NHGRI), NIH
- 2004-present** **Adjunct Assistant Professor**
Johns Hopkins Bloomberg School of Public Health
Department of Health, Behavior, and Society, Baltimore, MD
- 2003-present** **Faculty**
Section on the Ethics of Genetics and Emerging Technologies
NIH IRB Internship Program Director
Department of Bioethics, Clinical Center, NIH, Bethesda, MD

EDUCATION

Ph.D., 1999
Program in Law, Ethics, and Health
Department of Health Policy and Management
Johns Hopkins School of Public Health, Baltimore, MD

B.A., 1993
Department of Biology
Brandeis University, Waltham, MA

PREVIOUS POSITIONS

- 2003-2005** **Associate Investigator**
Social and Behavioral Research Branch, NHGRI, NIH

- 2000-2003 Bioethicist**
Bioethics Research Section, Medical Genetics Branch NHGRI, NIH
- 1999-2000 Bioethicist**
Office of Bioethics and Special Populations Research
Office of the Clinical Director, NHGRI, NIH
- 1999-2003 Special Expert**
Section on Ethics and Genetics, Department of Clinical Bioethics, Clinical Center, NIH
- 1995-1999 Project Director**
“Privacy, Confidentiality, and Health Insurance”
Johns Hopkins Bioethics Institute, Baltimore, MD
- 1994-1995 Research Associate**
Advisory Committee on Human Radiation Experiments, Washington, DC
- 1994 Research Assistant**
“Societal Responses to the Reproductive Decisions of HIV-Infected Women,” Johns Hopkins School of Public Health, Baltimore, MD

ACTIVE BOARDS AND OTHER POSITIONS

- Since 2020 Co-Chair**
IRB Working Group on Genomic Research Results, NIH
- Since 2020 Member**
Sub-Committee on Harmonizing NIH Informed Consent Language Options for Broad Data Sharing, EAWG-OSP, NIH
- Since 2014 Member**
NHGRI Genomic Data Sharing Policy Governance Committee
- Since 2013 Member**
Observational Safety Monitoring Board, Pediatric Cardiac Genomics Consortium, Bench-to-Bassinet Program, NHLBI, NIH
- Since 2011 Member**
Ethics Working Party, International Stem Cell Forum
- Since 2011 Member**
Administrative Review Committee (for Research with hESCs), NIH
- Since 2003 Member**
Ethics Committee, Clinical Center, NIH

PAST BOARDS AND OTHER POSITIONS

- 2018-2019 Co-Chair**
NIH General Medicine IRB Panel #1
- 2017-2019 Member**
Core Conference Planning Committee
Public Responsibility in Medicine and Research (PRIM&R)
- 2016-2019 Member**
Exceptions Subcommittee, NIH Single IRB Policy Implementation Committee
- 2014-2018 Chair** (*member since 2003*)
NHGRI Institutional Review Board, NIH
- 2014 Member**
NHGRI Genomic Data Sharing Implementation Working Group
- 2007-2014 Vice-Chair**
NHGRI Institutional Review Board, NIH
- 2013-2014 Member**
Trans-NIH Genomic Data Sharing Policy Implementation Committee
- 2013-2015 Member**
External Advisory Group, Autosomal Dominant Polycystic Kidney Disease (ADPKD) Modifiers Study, NIDDK, NIH
- 2010-2013 Member**
Human Subjects Working Group, NIH Genomic Data Sharing Policy, NIH
- 2013-2015 Member**
External Advisory Group, Autosomal Dominant Polycystic Kidney Disease (ADPKD) Modifiers Study, NIDDK, NIH
- 2012 Co-Chair**
Conference on Whole Genome Approaches to Complex Kidney Diseases, NIDDK, Rockville, MD
- 2010-2012 Editorial Board Member**
American Journal of Bioethics – Primary Research
- 2007-2010 Bioethics Consultant**
Collaboration, Education, Test Translation Program, ORD, NIH

- 2008-2009 Member**
Genetic Information Advisory Group
National Center for Biotechnology Information and DDIR, NIH
- 2004-2007 Member**
Human Tissue/Specimen Banking Working Group
National Cancer Institute/Public Responsibility in Medicine & Research
- 2003 Member**
National Collaborative Network for Ophthalmic Research and Diagnostic
Genotyping, National Eye Institute, NIH
- 2001 Section Chair**
Forum on Bioethics, American Public Health Association
- 2000 Program Chair**
Forum on Bioethics, American Public Health Association Annual Meeting
and Exposition
- 1997-1998 Member**
Committee on Human Research, Johns Hopkins University School of
Public Health
- 1993-1994 Member**
Animal Care/Use Committee, Johns Hopkins School of Public Health

AWARDS AND HONORS

- 2019 Director's Distinguished NHGRI Group Award, Bioethics Core**, "For extraordinary group contributions in advancing the mission of the National Human Genome Research Institute"
- 2019 NIH Director's Award** "In recognition of the successful formation of the first consolidated IRB, General Medicine 1, paving the path towards development of a fully centralized Institutional Review Board for the NIH."
- 2018 NHGRI GREAT Award (Group/Bioethics Core Pilot IRB Transition Team)** "For extraordinary leadership and collegial engagement in support of the NIH IRB reorganization and the successful creation of a new consolidated pilot IRB"
- 2018 OD Honor Award (Group)** as part of the Pilot Institutional Review Board.

- 2017** **NIH Director's Award (Group)** "For exceptional initiative in enhancing the cultural competency and sensitivity of the NIH IRB Internship Program"
- 2016** **NIH Director's Award** "For exceptional performance as Director of NHGRI's Bioethics Core and Chair of NHGRI IRB, and a role model for the entire NIH Intramural Research Program"
- 2016** **NIH Director's Award (Group)** "For developing the trans-NIH Clinical Center Genomics Opportunity (CCGO) program, which establishes the first NIH Clinical Center genomic test with CLIA-compliant exome sequencing."
- 2014** **NHGRI GREAT Award/Diversity and Community Outreach** "For developing an innovative internship program to increase Native American and Alaska Native involvement in the NIH IRB community."
- 2011** **NIH Director's Award** "For significant achievements in helping intramural researchers and IRB's navigate the complex ethical terrain associated with next generation sequencing research."
- 2011** **NHGRI GREAT Award/Scientific Medical Achievement** "For the significant efforts to help intramural researchers and IRB's navigate the complex ethical terrain associated with next generation sequencing research."
- 2007** **NIH Award of Merit** "For outstanding performance in organizing the NHGRI IRB Office"
- 2006** **NIH Award of Merit** "For advancing NHGRI's public education and outreach mission"
- 2001** **NIH Award of Merit** "For organizing a monthly ethics case conference for NHGRI"
- 1999-2003** **NIH Loan Repayment Program for General Research**
- 1999** **NIH Award of Merit** "For outstanding effort in establishing & organizing the NHGRI IRB"
- 1997-1998** **Cystic Fibrosis Foundation Student Traineeship Grant**
- 1997-1999** **Maryland State Senatorial Scholarship**
- 1989-1993** **Justice Louis D. Brandeis Scholar's Program**
- 1989-1993** **Evelyn Fraites Scholarship for Liberal Arts**

1991-1992 Brandeis University Undergraduate Fellows Program

PUBLICATIONS

BOOKS AND BOOK CHAPTERS

Hull SC and Rodriguez LL (in press) "Return of Results – Secondary Findings," in Liz Bankert, Bruce Gordon, Elisa Hurley, and Sharon Shriver, eds. *IRB Management and Function, 3rd Edition*. Jones and Bartlett Learning.

Hull SC (2017) "Informed Consent for Genetic Research on Rare Diseases: Insights from Empirical Research," in I. Glenn Cohen, H Lynch, and B. Bierer, eds. *Specimen Science: Ethics and Policy Implications*. MIT Press.

Danis M, Largent E, Wendler D, **Hull SC**, Shah S, Millum J, Berkman BE, Grady C (2012) *Research Ethics Consultation: A Case Book*, Oxford University Press.

Berkman BE and **Hull SC** (2012) "Ethical Issues in Genomic Databases," *Encyclopedia of Applied Ethics (Second Edition)*, Elsevier, 488-496.

Taylor HA, **Hull SC**, and Kass NE (2010) "Qualitative Research," in J. Sugarman and DP Sulmasy, eds. *Methods in Medical Ethics, 2nd Edition*, Washington, DC: Georgetown University Press, pp. 193-214.

Hull SC, Taylor HA, and Kass NE (2001) "Qualitative Research," in J. Sugarman and DP Sulmasy, eds. *Methods in Medical Ethics, 1st Edition*, Washington, DC: Georgetown University Press, pp. 146-168.

JOURNALS

Hull SC (2019) Changing the Conversation about The Ethics of Genomics and Health Disparities Research with American Indian and Alaska Native Communities: A Report from the Field. *Journal of Health Care for the Poor and Underserved*. 30(4) Supplement, 21-26.

Walajahi H, Wilson DR, **Hull SC** (2019) Constructing Identities: The Implications of DTC Ancestry Testing for Tribal Communities. *Genetics in Medicine*. *Epub ahead of print*.

Hull SC and Schiffenbauer AI (2019) Single IRBs Are Responsible to Ensure Consent Language Effectively Conveys the Local Context. *Am J Bioeth*. 19(4):85-86.

Sullivan HK, Bayefsky M, Wakim P, Huddleston K, Biesecker BB, Hull SC, Berkman BE (2019) Non-Invasive Prenatal Whole Genome Sequencing: Pregnant Women's Views and Preferences. *Obstetrics and Gynecology*. 133(3):525-32.

Splinter K, **Hull SC**, Holm IA, McDonough TL, Wise AL, Ramoni RB; Members of the Undiagnosed Diseases Network (2018) Implementing the Single Institutional Review Board Model: Lessons from the Undiagnosed Diseases Network. *Clin Transl Sci*. 11(1):28-31.

Hull SC, Wilson DR (2017) Beyond Belmont: Ensuring Respect for AI/AN Communities Through Tribal IRBs, Laws, and Policies. *Am J Bioeth*. 17(7):60-62.

Doernberg S and **Hull SC** (2017) Harms of Deception in FMR1 Premutation Genotype-Driven Recruitment. *American Journal of Bioethics*. 17(4):62-63.

Chen S, Berkman BE, **Hull SC** (2017) Recontacting Participants for Expanded Uses of Existing Samples and Data: A Case Study. *Genetics in Medicine*. 19(8):883-889.

Bayefsky MJ, White A, Wakim P, **Hull SC**, Wasserman D, Chen S, and Berkman BE (2016) Views of American OB/GYNs on the ethics of prenatal whole genome sequencing. *Prenatal Diagnosis* 36(13):1250-1256.

Koretsky M, Bonham VL, Berkman BE, Kruszka P, Adeyemo A, Muenke M, **Hull SC** (2016) Towards a More Representative Morphology: Clinical and Ethical Considerations for Including Diverse Populations in Diagnostic Genetic Atlases. *Genetics in Medicine* 18(11):1069-74.

Ortiz R, **Hull SC**, Colloca L (2016) Patient Attitudes about the Clinical Use of Placebo: Qualitative Perspectives from a Telephone Survey." *BMJ Open* 6(4):e011012.

Darnell AJ, Austin H, Bluemke DA, Cannon RO 3rd, Fischbeck K, Gahl W, Goldman D, Grady C, Greene MH, Holland SM, **Hull SC**, Porter FD, Resnick D, Rubinstein WS, Biesecker LG (2016) A Clinical Service to Support the return of Secondary Genomic Findings in Human Research. *Am J Hum Genet* 98(3):435-41.

Gliwa C, Yurkiewicz I, Lehmann LS, **Hull SC**, Jones N, Berkman BE (2016) Institutional Review Board Perspectives on Obligations to Disclose Genetic Incidental Findings to Research Participants. *Genetics in Medicine* 18(7):705-11.

Berkman BE, **Hull SC**, Biesecker LG (2015) Scrutinizing the Right Not to Know. *Am J Bioeth* 15(7): 17-19.

Freeman B, Butler K, Bolcic-Jankovic D, Clarridge B, Kennedy C, LeBlanc J, **Hull SC** (2015) Surrogate Receptivity to Participation in Critical Illness Genetic Research. *CHEST*. 147(4):979-988.

Lomax GP, **Hull SC**, Isasi R (2015) The DISCUSS Project: Revised Points to Consider for the Derivation of Induced Pluripotent Stem Cell Lines from Previously Collected Research Specimens. *Stem Cells Transl Med*. 4(2):123-9.

Berkman BE, **Hull SC**, Eckstein L (2014) The unintended implications of blurring the line between research and clinical care in a genomic age. *Per Med*. 11(3):285-95.

Isasi R, Andress PW, Baltz JM, Bredenoord AL, Burton P, Chui IM, **Hull SC**, Jung JW, Kurtz A, Lomax G, Ludwig T, McDonald M, Morris C, Ng HH, Rooke H, Sharma A, Stacey GN, Williams C, Zeng F, Knoppers BM (2014) Identifiability and Privacy in Pluripotent Stem Cell Research. *Cell Stem Cell*. 14(4):427-30.

Berkman BE and **Hull SC** (2014) The “Right Not-to-Know” in the Genomic Era: Time to Break from Tradition? *Am J Bioeth* 14(3):28-31.

Bharti K, Rao M, **Hull SC**, Stroncek D, Brooks B, Feigal E, van Meurs J, Huang C, Miller S (2014) Developing cellular therapies for retinal degenerative diseases. *Investigative Ophthalmology & Visual Science* 55(2):1191-202.

Hull SC and Berkman BE (2014) Ahead of the Curve: Grappling with Genomic Incidental Findings in the Clinical Realm. *CHEST* 145(2):226-230.

Shah SK, **Hull SC**, Spinner MA, Berkman BE, Sanchez LA, Abdul-Karim R, Hsu AP, Claypool R, Holland SM (2013) What does the duty to warn require? *Am J Bioeth* 13(1):62-3.

Lomax GP, **Hull SC**, Lowenthal J, Rao M, Isasi R. (2013) The DISCUSS Project: Induced pluripotent stem cell lines from previously collected research biospecimens and informed consent. Points to Consider. *Stem Cells Transl Med* 2(10):727-30.

Lowenthal J and **Hull SC** (2013) Framing the “Right to Withdraw” in the Use of Biospecimens for iPSC Research. *Ethics in Biology, Engineering, and Medicine: An International Journal* 4(1): 1–14.

Hull SC, Colloca L, Avins A, Gordon NP, Somkin CP, Silver P, Kaptchuk TJ, Miller FG (2013) A Survey of Patients’ Attitudes about the Use of Placebo Treatments. *BMJ* 347:f3757.

Abdul-Karim R, Berkman BE, Wendler D, Rid A, Khan J, Badgett T, **Hull SC** (2013) Disclosure of incidental findings from next-generation sequencing in pediatric genomic research. *Pediatrics*. 131(3):564-71.

Donley G, **Hull SC**, Berkman BE (2012) Prenatal Whole Genome Sequencing: Just Because We Can, Should We? *Hastings Cent Rep*. 42(4):28-40.

Lowenthal J, Lipnick S, Rao M, **Hull SC** (2012) Specimen Collection for Induced Pluripotent Stem Cell Research: Harmonizing the Approach to Informed Consent. *Stem Cells Transl Med*. 1(5):409-421.

Hull SC, Chan B, Biesecker LG, Berkman BE (2012) Response to Open Peer Commentaries on “Genomic Inheritances: Disclosing Individual Research Results from Whole-Exome Sequencing to Deceased Participants’ Relatives.” *Am J Bioeth.* 12(12):W9-W10.

Chan B, Fabio F, Eidem H, Biesecker L, **Hull SC**, Berkman BE (2012) Genomic Inheritance: A Case for Disclosing Research Results Deceased Participants’ Relatives. *Am J Bioeth.* 12(10):1-8.

Lowenthal J, **Hull SC**, Pearson SD (2012) The Ethics of Early Evidence: Preparing for a Possible Breakthrough in Alzheimer’s Disease. *NEJM.* 367(6): 488-90.

Isasi R, Knoppers BM, Andrews PW, Bredenoord A, Colman A, Hin LE, **Hull SC**, Kim OJ, Lomax G, Morris C, Sipp D, Stacey G, Wahlstrom J, Zeng F; International Stem Cell Forum Ethics Working Party (2012) Disclosure and Management of Research Findings in Stem Cell Research and Banking: Policy Statement. *Regen Med.* 7(3):439-48.

Rubinstein YR, Groft S, **Hull SC**, Kaneshiro J, Karp B, Lockhart NC, Marshall PA, Moxley RT, Pollen GB, Miller VR, Schwartz J (2012) Informed Consent Process for Patient Participation in Rare Disease Registries Linked to Biorepositories, *Contemporary Clinical Trials* 33: 5-11.

Tabor HK, Berkman BE, **Hull SC**, Bamshad MJ (2011) Genomics Really Gets Personal: How Exome and Whole Genome Sequencing Challenge the Ethical Framework of Human Genetics Research. *Am J Med Genet A.* 155A(12): 2916-24.

Goldenberg AJ, **Hull SC**, Wilfond BS, Sharp RR (2010) Patient Perspectives on Group Benefits and Harms in Genetic Research. *Public Health Genomics.* 2011;14(3):135-42.

Rubinstein YR, Groft SC, Bartek R, Brown K, Christensen RA, Collier E, Farber A, Farmer J, Ferguson JH, Forrest CB, Lockhart NC, McCurdy KR, Moore H, Pollen GB, Richesson R, Miller VR, **Hull SC**, Vaught J. (2010) Creating a Global Rare Disease Patient Registry Linked to a Rare Diseases Biorepository Database: Rare Disease-HUB (RD-HUB) *Contemp Clin Trials.* 31(5):394-404.

Adikes KA, **Hull SC**, Danis M. (2010) The views of low-income employees regarding mandated comprehensive employee benefits for the sake of health. *Soc Work Public Health.* 25(1):102-23.

Sapp JC, **Hull SC**, Duffer S, Zornetzer S, Sutton E, Marteau TM, Biesecker BB. (2010) Ambivalence toward undergoing invasive prenatal testing: an exploration of its origins. *Prenatal Diagnosis.* 30(1):77-82.

Goldenberg AJ, **Hull SC**, Botkin JR, Wilfond BS. (2009) Pediatric Biobanks: Approaching Informed Consent for Continuing Research after Children Grow Up. *J Pediatr.* 155(4):578-83.

Hull SC, Sharp RR, Botkin JR, Brown M, Hughes M, Schwinn D, Sankar P, Sugarman J, Bolcic-Jankovic D, Clarridge BR, Wilfond BS (2008) Patients' Views on Identifiability of Samples and Informed Consent for Genetic Research. *Amer J of Bioeth.* 8(10): 62–70.

Kass NE, Medley AM, Natowicz MR, **Hull SC**, Faden RR, Plantinga L, Gostin LO (2007) Access to Health Insurance: Experiences and Attitudes of those with Genetic versus Non-Genetic Medical Conditions. *Am Journal Med Genet.* 143A(7): 707-717.

Grady C, Horstmann E, Sussman JS, **Hull SC** (2006) The Limits of Disclosure: What Research Subjects Want to Know about Investigator Financial Interests. *Journal of Law, Medicine & Ethics*, 34(3): 592-599.

King NM, Henderson GE, Churchill LR, Davis AM, **Hull SC**, Nelson DK, Parham-Vetter PC, Rothschild BB, Easter MM, Wilfond BS. (2005) Consent Forms and the Therapeutic Misconception: The Example of Gene Transfer Research. *IRB.* 27(1):1-8.

Leib JR, Gollust SE, **Hull SC**, Wilfond BS (2005) Carrier Screening Panels for Ashkenazi Jews: Is More Better? *Genetics In Medicine.* 7(3):185-90.

Hurst S, **Hull SC**, Duval G, Danis M (2005) Physicians' Responses to Resource Constraints. *Archives of Internal Medicine.* 165(6):639-44.

Hurst S, **Hull SC**, Duval G, Danis M (2005) How Physicians Face Ethical Difficulties: a Qualitative Analysis. *Journal of Medical Ethics.* 31(1):7-14.

Hull SC, Glanz K, Steffen A, Wilfond (2004) "Recruitment Approaches for Family Studies: Attitudes of Index Patients and Their Relatives." *IRB: Ethics & Human Research*, 26(4): 12-18.

Hull SC, Gooding H, Klein AP, Warshauer-Baker E, Metosky S, Wilfond BS (2004) Genetic Research Involving Human Biological Materials: A Need to Tailor Consent Forms. *IRB: Ethics & Human Research* 26(3): 1-7

Kass NK, **Hull SC**, Natowicz NR, Faden RR, Plantinga L, Gostin LO, Slutsman J (2004) Medical Privacy and the Disclosure of Personal Medical Information: The Beliefs and Experiences of Those With Genetic and Other Clinical Conditions. *American Journal of Medical Genetics*, 128A: 261-270

Kass NE, Natowicz MR, **Hull SC**, Faden RR, Plantinga L, Gostin LO, Slutsman J (2003) The Use of Medical Records in Research: What Do Patients Want? *Journal of Law, Medicine & Ethics.* 31:429-433

Gollust SE, Wilfond BS, **Hull SC** (2003) Direct-to-Consumer Sales of Genetic Services on the Internet. *Genetics In Medicine.* 5(4):332-337

Plantinga L, Natowicz NR, Kass NE, **Hull SC**, Gostin LO, and Faden RF (2003) "Disclosure, Confidentiality, and Families: Experiences and Attitudes of Those with Genetic Versus Non-Genetic Medical Conditions," *American Journal of Medical Genetics*, 119C:51-59.

Gollust S, **Hull SC**, Wilfond B, (2002) "The Limitations of Direct-to-Consumer Advertising for Clinical Genetic Testing," *JAMA*, 288(14): 1762-1766.

Davis A, **Hull SC**, Grady C, Wilfond B, and Henderson G (2002) The Invisible Hand in Clinical Research: The Study Coordinator's Critical Role in Human Subjects Protection. *Journal of Law, Medicine, and Ethics*. 30(3): 411-419.

Hull SC and Prasad K (2001) Reading Between the Lines: Direct-to-Consumer Advertising of Genetic Testing. *Hastings Center Report*, 31(3): 33-35 [reprinted in *Reproductive Health Matters*. 2001;9(18):44-48].

Silverman H, **Hull SC**, and Sugarman J (2001) Variability Among Institutional Review Boards' Decisions Within the Context of a Multi-Center Trial. *Critical Care Medicine*. 29(2):235-241.

Hull SC and Kass NE (2000) Adults with Cystic Fibrosis and (In)fertility: How Has the Health Care System Responded? *Journal of Andrology*. 21(6): 809-813.

PRESENTATIONS

Professional Conferences:

"Complex Institutional Relationships--Going Beyond the Multi-Site Model," 11/2019, Panelist, PRIM&R Annual Advancing Ethical Research Conference, Boston, MA

"Sovereignty in Research" Moderator, 11/2017
PRIM&R Annual Advancing Ethical Research Conference, San Antonio, TX

"Exceptional Cases and Broad Consent for Genomic Research: What Can Data Tell Us?" as part of a panel discussion on "Changing the Model—Participant Permissions for Broad Data Sharing: Pros, Cons, and Practice in Real Life," 10/16
18th Annual Meeting of the American Society for Bioethics and Humanities, Washington, DC

Moderator, "Preserving a Role for Tribal Review of Research in the Context of Single IRB Policies," 9/16
PRIM&R Webinar (see <http://www.primr.org/webinars/sept2016/>)

"Overview of Human Subjects Protections," 6/16
Preconference Workshop: IRB Training, 26th National Native Health Research

Conference, Native Research Network, Cherokee, NC

“Opportunities and Obstacles in the Commercialization of Induced Pluripotent Stem Cells: Cell Sourcing,” 2/14
Annual Meeting of the Association of University Technology Managers, San Francisco, CA

“Commercialization of Induced Pluripotent Stem Cells: Ethical Considerations,” 3/13
Annual Meeting of the Association of University Technology Managers, San Antonio, TX

“Emerging Issues in WGS: Informed Consent and Beyond,” 12/11
PRIM&R Advancing Ethical Research Conference, National Harbor, MD

“The \$1,000 Genome: Ethical Implications of Whole Exome and Whole Genome Sequencing,” 10/10
12th Annual Meeting of the American Society of Bioethics and Humanities Annual Meeting, San Diego, CA

“Biobanks: Public Concerns about Financial Interests and Policy Options,” 10/06
American Society of Bioethics and Humanities Annual Meeting, Denver, CO

“Hope in Clinical Trials” (moderator), 10/04
American Society of Bioethics and Humanities Annual Meeting, Philadelphia, PA

“How Much Should Public Preferences Count in Crafting Public Policy?” 6/04
Bioethics 2004: 16th Annual Bioethics Retreat, Wintergreen, VA

“Great Expectations: Describing Media Representations of Genetics and their Influence on Consumers’ Perceptions” (moderator), 10/02
American Society for Bioethics and Humanities Annual Meeting, Baltimore, MD

“The Invisible Hand in Clinical Research: The Study Coordinator’s Critical Role in Human Subjects Protection”, 10/01
American Society for Bioethics and Humanities Annual Meeting, Nashville, TN

“Variations in Informed Consent Practices for Genetic Research,” 10/01
American Society of Human Genetics Annual Meeting, San Diego, CA

“Reproductive Experiences and Plans of Adults with Sickle Cell Disease and Cystic Fibrosis: A Qualitative Study,” 11/98
American Public Health Association Annual Meeting, Washington, DC

“Reproductive Decision-Making & Counseling of Adults with Cystic Fibrosis & Sickle Cell Disease,” 11/97
American Public Health Association 125th Annual Meeting, Indianapolis, IN

“Electronic Mailing Lists and Research Ethics: The Case of an Electronic Cystic Fibrosis Discussion Group,” 11/97
Joint Meeting of the American Association of Bioethics, Society for Bioethics Consultation, and Society for Health and Human Values, Baltimore, MD

“Reproduction and Adults with Genetic Conditions: Perspectives of Adults with Cystic Fibrosis and Sickle Cell Disease and Their Health Care Providers,” 11/97
Joint Meeting of the American Association of Bioethics, Society for Bioethics Consultation, and Society for Health and Human Values (Baltimore, MD)

Invited Seminars and Workshops:

“Ethics of Ancestry Testing in Cancer Clinical Research” 10/1/2019
ENRICH Forum, National Cancer Institute, Rockville, MD

“Invited Plenary: The Unnatural Causes of Health Inequalities and Inequity,” 1/24/2019
Second Conference on Bioethics Issues in Minority Health and Health Disparities Research, U54 Morehouse School of Medicine/Tuskegee University/University of Alabama at Birmingham Cancer Research Partnership, Opelika, AL

“NIH Data Sharing Policies: Honoring the Exceptions and Alternatives,” 7/2018
Alaska Native Genomics Research Workshop, Southcentral Foundation, Anchorage, AK

“Bioethics and Research Regulation: The Evolution of Human Subjects Protections in the U.S.” 7/2018
Educational Session, Alaska Native Tribal Health Corporation, Anchorage, AK

“The Changing Landscape of IRBs: From Barbarians to All of Us” 10/2017
Annual NHGRI Symposium, NIH

“The Ethics of Genetic Research with Stored Samples,” 9/2016, 9/2017
NHGRI International Summit in Human Genetics and Genomics, NIH

“NIH sIRB and GDS Policies: Honoring Exceptions, Limitations, & Alternatives” 9/2017
Tribal Advisory Committee Meeting, NIH

“IRB Review and Approval of Research, Including Research with Tribal Populations”
2/2017
Consultation with Tribal Nations, NIH

“The IRB’s Role in Risk Determinations for Genomic Research IDEs,” 6/16
NHGRI IDEs and Genomics Workshop, Rockville, MD

“The Ethics of Research with Human Participants: Tuskegee and Today,” 5/16

Wheaton High School Biomedical Academy, Wheaton, MD

- “On Becoming the Central IRB of Record for a Multi-Site Study: Opportunities, Challenges, and Lessons Learned,” 4/16
Protocol Navigation Training Program, NIH
- “Ethical Review of Research with Tribal Communities: NIH Training Opportunities,” 2/16
Tribal Consultation Advisory Committee, NIH
- “Informed Consent for Genetic Research on Rare Diseases: Insights from Empirical Research” 11/15
Specimen Science: Ethics and Policy Implications, The Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics at Harvard Law School, Cambridge, MA
- “IRB Perspectives on Genomic Data Sharing and Informed Consent at NIH,” 10/15
Combined NeuroSciences IRB Retreat, NIH
- “The Ethics and Wisdom of Broad Consent for Genomic Research,” 6/15
Second International Conference on Rare and Undiagnosed Diseases, Budapest, Hungary
- “Ethical Considerations in Research involving the Collection and Analysis of Human Genetic Data,” 2/15
Genetic Testing and Research Agency Policy Meeting, NASA, Houston, TX
- “Planning the Study: ELSI Issues in Study Design and Governance” (Moderator), 1/15
Workshop to Explore the Ethical, Legal, and Social Implications of Citizen Science Related to the NIH Mission, NIH, Rockville MD
- “The Ethics of Genetic Research with Stored Samples and Data,” 10/14
Office of Minority Health Lecture Series, FDA, Silver Spring, MD
- “Whole Genome Sequencing in the Clinical Setting: The Ethics of “Too Much” Information”, 5/14
Workshop on Philosophical Problems in Personalised Medicine; Department of Philosophy, Logic, and Scientific Method; London School of Economics, UK
- “The Ethics of Genetic Testing in the Research Setting: The Challenge of Informed Consent” 12/13
NINDS Grand Rounds Lecture, NIH
- “Biospecimen Donation, iPSCs, and Informed Consent: Anticipating Future Therapeutic Applications” 6/13
Tissue Sourcing Session, Working Together Towards A Cell-Based IND, National Eye Institute and National Institutes for Regenerative Medicine, NIH

- “Anticipating the Ethics of Genomic Research,” 5/13
Process of Discovery Series, Medical Research Scholars Program, NIH
- “The Impact of *The Immortal Life of Henrietta Lacks* on the Field of Bioethics” 3/13
Drew University, Madison, NJ.
- “Protecting Human Subjects in Genomic Research” 12/12
International Bioethics Symposium, Peking Union College of Medicine
Beijing, China.
- “Stem Cell and Regenerative Medicine Research and Informed Consent” 12/12
International Bioethics Symposium, Peking Union College of Medicine
Beijing, China.
- “Deceased Donor Specimens, iPS Cell Research, and Next-of-Kin Authorization,” 11/12
Berman Institute of Bioethics Seminar Series, Johns Hopkins, Baltimore, MD
- “Ethical and IRB Issues Related to Whole-Genome Sequencing,” 10/12
NCI Technology Transfer Seminar Series, Rockville, MD
- “Stem Cell Research and Informed Consent: Balancing Hope and Uncertainty” 5/12
STEP Forum: *Stem Cell Therapy: Hype and Reality*, NIH
- “Pediatric Biospecimens and Informed Consent when Children Reach Adulthood:
Preferences and Practices” 3/12
NIH Biospecimens Interest Group, NIH
- “Ethical Challenges Associated with Genomic Sequencing in the Clinical Setting” 5/11
STEP Forum: Knowing our DNA Sequence: What it Means for You and Me, NIH
- “Identifiability: A Useful or Decrepit Concept in Research Ethics? 10/10
DHHS Secretary’s Advisory Committee on Human Research Protections,
Washington, DC
- “Ethics Review of Next Generation Sequencing Research at NIH: A Primer and a
Proposal” 7/10
Human Subjects Research Advisory Committee, NIH
- “Ethics and Genomic Research: Scrambling Through the Bottleneck” 4/10
SoCRA Legal, Ethical and Practical Considerations in Protecting Human
Research Participants Workshop, Philadelphia, PA
- “Ethics and Genomic Databases: Scrambling Through the Bottleneck” 3/10
Departmental Colloquium in Bioinformatics and Computational Biology, George
Mason University, Manassas, VA

- “Ethical Issues in the Use of Stored Samples” 8/09
Fisher BioServices IRB Retreat, Rockville, MD
- “The Ethical Introduction of New Tests into Clinical Practice: XDR-TB and the Genotype MTBDR Line Probe Assay” 6/09
Division of AIDS, NIAID, NIH, Rockville, MD
- “Ethical Issues in the Use of Stored Samples” 6/09
IRB Retreat, NIEHS, NIH, Chapel Hill, NC
- “Patient Attitudes Regarding Genetic Research with Stored Samples” 8/09
Trans-NIH Bioethics Committee, NIH, Rockville, MD
- “Genetic Research on Samples from the Deceased: Regulatory Ambiguities and Ethical Issues” 12/09
Institutional Review Board, National Cancer Institute, NIH
- “The Genetic Information Nondiscrimination Act of 2008: Implications for Genetic Research and Informed Consent” (panel presentation), 11/08
Inter-Institute Bioethics Interest Group, NIH
- “What Makes Genetic Research Ethical?” 9/08
Prince George’s County Community College, College Park, MD
- “Ethics and Regulation of Genetic Research with Stored Samples & Data” 4/08
NIH Intramural Sequencing Center, NIH
- “Research with Human Biological Materials,” 9/05
Conference on Emerging Issues in Research with Human Subjects,
NIEHS/PRIM&R, Chapel Hill, NC
- “Issues Surrounding the Use of Human Biological Materials in Research,” 7/05
NCI Combined Faculty Retreat, Cumberland, MD
- “Qualitative Research Design: Strategies for Genetic Counselors,” 10/04
National Society of Genetic Counselors 23rd Annual Education Conference,
Washington, DC
- “Patients’ Perspectives on Genetic Research with Their Blood Samples;” 5/04
Conference on Conflicts of Interest, Privacy/Confidentiality, and Tissue
Repositories, PRIM&R and Columbia University College of Physicians and
Surgeons, Boston, MA
- “‘Bringing You the World of Genetics’ - The ethical implications of direct-to-consumer
advertising and direct sales of genetic tests.” 3/04

NHGRI Workshop on Direct to Consumer Advertising Of Genetic Tests,
Bethesda, MD

“Q&A on Ethical Issues in Genetic Research,” 9/03

Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

“Qualitative Research: Social Science in Genetics,” 6/03

National Society of Genetic Counselors Grant Writing Seminar, Baltimore, MD

“Direct-to-Consumer Advertising of Genetic Testing: Some Ethical Issues,” 4/03

Cornell-In-Washington Program, Bethesda, MD

“Postmortem Confidentiality of Genetic Research Results,” 9/01

Division of Cancer Epidemiology and Genetics, National Cancer Institute, NIH,
Bethesda, MD

“Nurse Rivers' Dilemmas: Research Relationships, Ethics, and the Study Coordinator,”
4/01

AFFIRM Annual Meeting, Washington, DC

“Ethical Implications of Human Genome Research and its Application,” Conference on
Brain Research and the Mapping of the Human Genome: Applications to Primary
Care and Psychiatric Medicine, 3/00

Co-sponsored by the Washington Psychiatric Society in collaboration with the
Medical Society of the District of Columbia, George Washington University,
Washington, DC

“Research Ethics: The Goal of Informed Consent in Subject Recruitment and
Retention,” 9/99

AFFIRM Annual Meeting, Washington, DC

“Special Issues in Genetic Research,” 2/99

Research Ethics Course (306.665), Department of Health Policy, Johns Hopkins
School of Public Health

“Genetic Exceptionalism, Privacy, and Public Policy,” 11/98

Science Studies Reading Group, Department of Science and Technology
Studies, Cornell University, Ithaca, NY

“Genetics, Public Policy, and Privacy,” 4/98

Genetic Soup Seminar, Dept. of Medical Genetics, Johns Hopkins Hospital

TEACHING

Coursework

- 2015-present **Lecturer**—“The IRB: Purpose, Function, and Proposals for Improvement,” annual session in Ethical and Regulatory Aspects of Clinical Research, Department of Bioethics, NIH
- 8/14 **Lecturer**—The Ethics of Involving Diverse Groups in Genomics Research: Balancing the Goals of Inclusiveness and Minimizing Harms, NIMHD Translational Health Disparities Course, NIH
- 5/12 **Lecturer**—Points to Consider in the Transition Toward Whole-Genome Sequencing in Human Subjects Research, Protocol Navigation Training Seminar, NIH
- 12/11 **Lecturer**—Ethics and IRB Issues Related to Whole-Exome Sequencing, Next-Gen 101: A How-To for Whole-Exome Sequencing Research, NIH
- 2006-present **Lecturer**— Ethical Issues in Genetic Research, Current Topics in Genomic Research Short Course, NHGRI, NIH
- 2003- present **Discussion Moderator**—Responsible Conduct of Research Training, Division of Intramural Research, National Human Genome Research Institute, NIH
- 2003-present **Lecturer**—“Ethical Issues in the Use of Stored Tissue,” annual session in Ethical and Regulatory Aspects of Clinical Research, Department of Bioethics, NIH
- 1/04-3/04 **Instructor**—Introduction to Qualitative Research, Joint Genetic Counseling Training Program, Johns Hopkins Bloomberg School of Public Health and National Human Genome Research Institute, NIH
- 2002 **Co-Instructor**—Qualitative Research Methods (315.840 Special Studies and Research) Joint Genetic Counseling Training Program, Johns Hopkins Bloomberg School of Public Health and National Human Genome Research Institute, NIH
- 1999-present **Lecturer**—Joint Genetic Counseling Training Program, Johns Hopkins Bloomberg School of Public Health and National Human Genome Research Institute, NIH. Annual lecture on “The NHGRI Institutional Review Board;” topical lectures on reproductive decision making, research role conflicts and informed consent

- 1998 **Grader**—*The Physician and Society*, Professors Leon Gordis and Henry Seidel, Johns Hopkins University School of Medicine
- 1997 **Teaching Assistant**—*Introduction to Health Policy and Management*, Professor Donald Steinwachs, Johns Hopkins P/T Graduate Program
- 1997; 1999 **Teaching Assistant**—*Research Ethics and Integrity*, Professor Nancy Kass, Johns Hopkins University School of Public Health

NIH IRB Internship Program Mentoring

- Fall 2018 Maureen Kombe, Zambia
- John Ipadeola, Nigeria
- Rizki Harnawan, Indonesia
- Fall 2017 Billy Wilson Nyambalo, M.S.
 National Health Sciences Research Committee, Malawi
- Kimberly Paul
 Blackfeet Nation (“Piikanii”), Montana, U.S.
- Gloria Maria Carmona Clavijo, MCH
 National Institute of Health, Ministry of Health, Peru
- Sithembile Ruzariro, MSc, MSocSC
 National Ethics Committee, Zimbabwe
- Sarah Lucía Carracedo Uribe, MA, LL.L.
 Institute of Tropical Medicine, National University of San Marcos, Peru
- Fall 2016 Flavia Ayebazibwe
 Uganda Virus Research Institute, Entebbe, Uganda
- Elvira Rohland
 Stellenbosch University, Cape Town, South Africa
- Sharmella Roopchand-Martin, DPT, MSc
 University of the West Indies, Kingston, Jamaica
- Warunee (“Tukta”) Thienkrua
 Thailand Ministry of Public Health – US CDC Collaboration
 Nonthaburi, Thailand

- Fall 2015 Adebayo Adejumo, PhD, MS, MHS
Member, National Health Research Ethics Committee of Nigeria
University of Ibadan, Nigeria
- Ado Danladi, BSC
Scientific Officer – National Health Research Ethics Committee, Federal
Ministry of Health, Nigeria
- Julia M. Lysander, MSC
Assistant Director for Operations, Liberia-US Joint Clinical Research
Program of the US NIH Ebola Response Program
- Cecelia Morris, MSN
Chair, University of Liberia IRB
- Gloria Mason, BA
Coordinator, National Research Ethics Board, PREVAIL- Liberia- US Joint
Clinical Research Program
- Spring 2015 Naomi Lee, PhD (Seneca Nation of New York)
ASERT-IRACDA Postdoctoral Fellow
Molecular Genetics and Microbiology, University of New Mexico
- Fall 2014 Helena Baidoo
Noguchi Memorial Institute for Medical Research, University of Ghana
- Changping (Julie) Zhu
Sun Yat-sen University, Guangzhou, China
- Segun Adeyemo
West African Bioethics Training Program, Nigeria
- Spring 2014 Deana Around Him, DrPH, ScM (Cherokee Nation of Oklahoma)
Johns Hopkins Bloomberg School of Public Health
- Mariddie Craig
White Mountain Apache Tribe Tribal Council
- Fall 2013 Noranjon Ayombekova, MA
PRISMA Research Center, Tajikistan
- Winfred Badanga Nazziwa, BA
Uganda National Council for Science and Technology
- Everlyne Ombati, BSc, MSc

Kenya Medical Research Institute (KEMRI) Center for Microbiology
Research

Olubusola Onasile, BS
West African Bioethics Training Program, Nigeria

Fall 2012 Stellah Imot, BA, PG
Makerere University College of Health Sciences, Uganda

C.S. Sreepriya, LL.B., MA, MBA
Sree Chitra Tirunal Institute for Medical Sciences and Technology, India

Bailu Wang, M.D., PhD
Shandong University School of Medicine, China

Fall 2011 Thang Cong Tran, MD
Thai Bing Medical University, Vietnam

Xiaomei Zhai, PhD
Chinese Academy of Medical Sciences and Peking Union Medical
College, China

Fall 2010 Eunji Lee, BSc
Korea Ministry of Health & Welfare

Hyen Oh La, M.Sc, PhD
College of Medicine at the Catholic University of Korea

Graduate Student Advising

2007-11 Darlene Perkins, PhD Dissertation, Graduate Partnership Program, NIH
and Johns Hopkins School of Nursing

2007-8 Jaclyn Douyard, Master's Thesis (co-advisor): "Disclosure of a Cystic
Fibrosis Diagnosis to a Dating Partner," Genetic Counseling Training
Program, Johns Hopkins Bloomberg School of Public Health and National
Human Genome Research Institute, NIH

2003 Karen Tam, Master's Thesis: "Genetic Information: Exploring the Value to
Adult Adoptees," Genetic Counseling Training Program, Johns Hopkins
Bloomberg School of Public Health and National Human Genome
Research Institute, NIH

2002 Chieko Tamura, Master's Thesis: "Japanese-Americans' and Japanese
People's Needs and Attitudes Toward Prenatal Genetic Counseling,"

Genetic Counseling Training Program, Johns Hopkins Bloomberg School of Public Health and National Human Genome Research Institute, NIH

Thesis Committee Participation

- 2010-11 Christy Haakonsen, Master's Thesis: "Assessing the Feasibility of Coping Effectiveness Training for Caregivers of Children with Autism Spectrum Disorders," Johns Hopkins Bloomberg School of Public Health and National Human Genome Research Institute, NIH
- 2005-6 Meredith Weaver, Master's Thesis: "How Do Genetic Counselors Define Advocacy in Their Profession?" Johns Hopkins Bloomberg School of Public Health and National Human Genome Research Institute, NIH
- 2003-4 Julie Chevalier Sapp, Master's Thesis: "Attitudes about amniocentesis among women of advanced maternal age," Johns Hopkins Bloomberg School of Public Health and National Human Genome Research Institute, NIH
- 2003 Valerie Brook Waggoner, Master's Thesis: "Exploration of Transitional Life Events in Individuals with Friedreich's Ataxia: Implications for Genetic Counseling," Genetic Counseling Training Program, Johns Hopkins Bloomberg School of Public Health and National Human Genome Research Institute, NIH
- 2002 Kira Apse, Master's Thesis: "Concerns about Genetic Discrimination: Origins and Effects," Genetic Counseling Training Program, Johns Hopkins Bloomberg School of Public Health and National Human Genome Research Institute, NIH