

## **CURRICULUM VITAE**

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### **CURRENT POSITIONS**

**Director**, Bioethics Core, 2004-present  
Office of the Clinical Director  
National Human Genome Research Institute (NHGRI)  
National Institutes of Health (NIH)

**Faculty**, Section on Ethics and Genetics, 2003-present  
Department of Bioethics  
Clinical Center, NIH  
Bethesda, MD

**IRB Vice-Chair**, 2007-present  
NHGRI Institutional Review Board, NIH

**Adjunct Assistant Professor**, 2004-present  
Johns Hopkins Bloomberg School of Public Health  
Department of Health, Behavior, and Society  
Baltimore, MD

**IRB Administrator**, 1999-present  
NHGRI Institutional Review Board, NIH

### **EDUCATION**

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

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

## **OTHER ACADEMIC AND PREVIOUS POSITIONS**

### **Associate Investigator, 2003-2005**

Social and Behavioral Research Branch, NHGRI, NIH

### **Bioethicist, 2000-2003**

Bioethics Research Section, Medical Genetics Branch NHGRI, NIH

### **Bioethicist, 1999-2000**

Office of Bioethics and Special Populations Research, Office of the Clinical Director, NHGRI, NIH

### **Special Expert, 1999-2003**

Section on Ethics and Genetics, Department of Clinical Bioethics, Clinical Center, NIH

### **Project Director, 1995-1999**

“Privacy, Confidentiality, and Health Insurance,” Johns Hopkins Bioethics Institute, Baltimore, MD

### **Research Associate, 1994-1995**

Advisory Committee on Human Radiation Experiments, Washington, DC

### **Research Assistant, 1994**

“Societal Responses to the Reproductive Decisions of HIV-Infected Women,” Johns Hopkins School of Public Health, Baltimore, MD

## **CURRENT AND PAST BOARDS AND OTHER POSITIONS**

### **Member, 2008-present**

Genetic Information Advisory Group

National Center for Biotechnology Information and Deputy Director of Intramural Research, NIH

### **Bioethics Consultant, 2007-present**

Collaboration, Education, and Test Translation (CETT) Program

Office of Rare Diseases, NIH

### **Member, 2004-2007**

Human Tissue/Specimen Banking Working Group

National Cancer Institute and Public Responsibility in Medicine and Research

### **Member, 2003-present**

Institutional Review Board, NHGRI, NIH

### **Member, 2003-present**

Ethics Committee, Clinical Center, NIH

**Member, 2003**

National Collaborative Network for Ophthalmic Research and Diagnostic Genotyping,  
National Eye Institute, NIH

**Section Chair, 2001**

Forum on Bioethics, American Public Health Association

**Program Chair, 2000**

Forum on Bioethics, American Public Health Association Annual Meeting and  
Exposition

**Member, 1997-1998**

Committee on Human Research, Johns Hopkins University School of Public Health

**Member, 1993-1994**

Animal Care/Use Committee, Johns Hopkins School of Public Health

**AWARDS AND HONORS**

**NIH Award of Merit, 2007**

“For outstanding performance in organizing and conducting the operations of the  
NHGRI IRB Office“

**NIH Award of Merit, 2006**

“For advancing NHGRI’s public education and outreach mission“

**NIH Award of Merit, 2001**

“For organizing a monthly ethics case conference for the NHGRI Intramural Program”

**NIH Loan Repayment Program for General Research, 1999-2003**

**NIH Award of Merit, 1999**

“For outstanding efforts in establishing and organizing the operation of an IRB for the  
NHGRI”

**Student Traineeship Grant, 1997-1998**

Cystic Fibrosis Foundation

**Maryland State Senatorial Scholarship, 1997-1999**

**Justice Louis D. Brandeis Scholar’s Program, 1989-1993**

**Evelyn Fraites Scholarship for Liberal Arts, 1989-1993**

**Brandeis University Undergraduate Fellows Program, 1991-1992**

## **PUBLICATIONS**

**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," *American Journal of Bioethics*, 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," *American Journal of Medical Genetics*, 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*, 2005,27(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

### **Book Chapters**

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

### **Letters**

**Hull SC** and Wilfond BS (2008) "What Does It Mean to Be Identifiable? Response to Peer Commentaries," *American Journal of Bioethics*, 8(10):W7

Gollust S, **Hull SC**, Wilfond B (2003) "Direct to Consumer Advertising for Genetic Testing (letter)," *JAMA*, 289(1): 446

## **PRESENTATIONS**

### ***Professional Conferences:***

“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<sup>P</sup> 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:***

“The Genetic Information Nondiscrimination Act of 2008: Implications for Genetic Research and Informed Consent” (panel presentation), 11/08  
Inter-Institute Bioethics Interest Group, NIH

“Ethical Issues in Genetic Research,” 9/08  
Prince George’s County Community College, College Park, MD

“Ethical Issues in Genetic Research,” 8/06, 8/07, 8/08  
Current Topics in Genomic Research Short Course, NHGRI, Bethesda, MD

“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 23<sup>rd</sup> 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*

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

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

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

### ***Advising***

- 2007-present Darlene Perkins, PhD Dissertation: “Perceptions of Genetic and Environmental Impact on Diabetes and Obesity: A Partnership with the Yup’ik Eskimo People of the Yukon Kuskokwim Delta.” 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***

- 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