

**CURRICULUM VITAE**  
**SARA CHANDROS HULL**

**PERSONAL DATA**

Bioethics Research Section	23425 Slidell Road
Medical Genetics Branch	Boyds, MD 20841
National Human Genome Research Institute	home phone: (301) 515-2499
National Institutes of Health	
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**EDUCATION**

- 1993 -1999 Ph.D.—Johns Hopkins School of Public Health; Department of Health Policy and Management; Program in Law, Ethics, and Health (Baltimore, MD).
- Dissertation Title: *Sickle Cell Disease, Cystic Fibrosis, and Reproduction: A Qualitative Study of Affected Adult and Health Care Provider Perspectives*
- 1989 - 1993 B.A.—Brandeis University, Department of Biology (Waltham, MA).

**PROFESSIONAL EXPERIENCE**

- 3/99-present Bioethicist—Bioethics Research Section, Medical Genetics Branch, National Human Genome Research Institute (NHGRI), National Institutes of Health (NIH) (Bethesda, MD).
- 3/99-present Research Specialist—Department of Clinical Bioethics, NIH.
- 9/95 – 3/99 Project Director—“Privacy, Confidentiality, and Health Insurance: Beliefs, Experiences, and Values of Patients and Families with Genetic and ‘Non-Genetic’ Conditions,” Johns Hopkins Bioethics Institute (Baltimore, MD).
- 6/94 - 10/95 Research Associate—Advisory Committee on Human Radiation Experiments (Washington, DC).
- 1/94 - 5/94 Research Assistant—“Societal Responses to the Reproductive Decisions of HIV-Infected Women,” Johns Hopkins School of Public Health.

## **CONSULTATIONS AND CURRENT RESEARCH PROJECTS**

- 1/00-present Principal Investigator—"Stored Tissue Research: Public Attitudes, Informed Consent, and Public Policy," Bioethics Section, NHGRI, NIH.
- 3/03-present Co-Investigator and Advisor—"Genetic Information: Exploring the Value to Adult Adoptees," thesis project of Karen Tam, Genetic Counseling Training Program, NHGRI, NIH.
- 8/02-present Co-Investigator—"Research Recruitment Strategies: Attitudes of Cancer Patients and Family Members," Bioethics Research Section, NHGRI, NIH.
- 3/02-12/02 Co-Investigator—"Japanese-Americans' and Japanese People's Needs and Attitudes Toward Prenatal Genetic Counseling," thesis project of Chieko Tamura, Genetic Counseling Training Program, NHGRI, NIH.
- 3/02-12/02 Associate Investigator—"Concerns about Genetic Discrimination: Origins and Effects," thesis project of Kira Apse, Genetic Counseling Training Program, NHGRI, NIH.
- 8/99-present Co-Principal Investigator—"The Study Coordinator: Defining Roles and Possible Role Conflicts," Bioethics Section, NHGRI, NIH.
- 4/99-present Associate Investigator—"Social Construction of Benefit in Gene Therapy Research, Bioethics and Special Populations Research Program," NHGRI, NIH.
- 3/99-present Consultant—"Privacy, Confidentiality, and Health Insurance: Beliefs, Experiences, and Values of Persons and Families with Genetic Conditions," Johns Hopkins Bioethics Institute.

## **HONORS AND AWARDS**

- 2001 National Institutes of Health Award of Merit, an outstanding job of organizing a monthly ethics case conference for the NHGRI Intramural Program
- 1999-present NIH Loan Repayment Program for General Research
- 1999 National Institutes of Health Award of Merit, for outstanding efforts in establishing and organizing the operation of an Institutional Review Board for the NHGRI
- 1997-1998 Student Traineeship Grant for dissertation research, Cystic Fibrosis Foundation
- 1997-1999 Maryland State Senatorial Scholarship
- 1989-1993 Justice Louis D. Brandeis Scholar's Program, Brandeis University
- 1989-1993 Evelyn Fraites Scholarship for Liberal Arts
- 1991-1992 Brandeis University Undergraduate Fellows Program

## PROFESSIONAL ACTIVITIES

American Public Health Association

- Program Chair, Forum on Bioethics, Year 2000 Annual Meeting and Exposition
- Section Chair, Forum on Ethics, Year 2001 Annual Meeting and Exposition

American Society for Bioethics and the Humanities

## PUBLICATIONS

### *Peer-Reviewed Articles*

Kass NK, **Hull SC**, Natowicz NR, Faden RR, Plantinga L, Gostin LO, Slutsman J (2003) "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*, in press.

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 (2003) "Direct to Consumer Advertising for Genetic Testing (letter)," *JAMA* 289(1): 446.

Gollust S, **Hull SC**, Wilfond B, (2002) "The Limitations of Direct-to-Consumer Advertising for 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.

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 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]

**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.

## **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.

## **Invited Book Reviews**

**Hull SC** (1999) review of: *Human Cloning: Religious Responses*, edited by Ronald Cole-Turner (Louisville, KY: Westminster John Knox Press, 1997) in *Religious Studies Review*, 25: 68.

**Hull SC** (1999) review of: *The Social Implications of Bioengineering*, by Elisabeth Beck-Gernsheim, (New Jersey: Humanities Press, 1995) in *Religious Studies Review*, 24: 397.

## **PRESENTATIONS**

### **Professional Conferences:**

- 10/27/02      **Hull SC**, Gollust SE, Geller G, Clayton J, Moderated panel discussion on: "Great Expectations: Describing Media Representations of Genetics and their Influence on Consumers' Perceptions," American Society for Bioethics and Humanities Annual Meeting (Baltimore, MD).
- 10/28/01      **Hull SC**, Davis A, Wilfond B, Grady C, Henderson G "The Invisible Hand in Clinical Research: The Study Coordinator's Critical Role in Human Subjects Protection (*Part I*)", American Society for Bioethics and Humanities Annual Meeting (Nashville, TN).
- 10/15/01      **Hull SC**, Gooding H, Metosky S, Warshauer- Baker E, Gutter E, Hurley E, Wilfond B, "Variations in Informed Consent Practices for Genetic Research," American Society of Human Genetics Annual Meeting (San Diego, CA)
- 11/17/98      **Hull SC**, and Kass NE, "Reproductive Experiences and Plans of Adults with Sickle Cell Disease and Cystic Fibrosis: A Qualitative Study," American Public Health Association Annual Meeting (Washington, DC).
- 11/10/98      **Hull SC**, and Kass NE, "Reproductive Decision-Making and Counseling of Adults with Cystic Fibrosis and Sickle Cell Disease," American Public Health Association 125th Annual Meeting (Indianapolis, IN).
- 11/7/97        **Hull SC**, "Electronic Mailing Lists and Research Ethics: The Case of an Electronic Cystic Fibrosis Discussion Group," Joint Meeting of the American Association of Bioethics, Society for Bioethics Consultation, and Society for Health and Human Values (Baltimore, MD).

11/8/97 **Hull SC**, and Kass NE, “Reproduction and Adults with Genetic Conditions: Perspectives of Adults with Cystic Fibrosis and Sickle Cell Disease and Their Health Care Providers,” Joint Meeting of the American Association of Bioethics, Society for Bioethics Consultation, and Society for Health and Human Values (Baltimore, MD).

***Invited Seminars:***

4/22/03 **Hull SC**, “Direct-to-Consumer Advertising of Genetic Testing: Some Ethical Issues,” Cornell-In-Washington Program (Washington, DC).

9/20/01 **Hull SC**, “Postmortem Confidentiality of Genetic Research Results,” Division of Cancer Epidemiology and Genetics, National Cancer Institute, NIH.

4/18/01 **Hull SC**, “Nurse Rivers' Dilemmas: Research Relationships, Ethics, and the Study Coordinator,” AFFIRM Annual Meeting (Washington, DC).

3/18/00 **Hull SC**, “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, co-sponsored by the Washington Psychiatric Society in collaboration with the Medical Society of the District of Columbia, George Washington University (Washington, DC).

9/17/99 **Hull SC**, “Research Ethics: The Goal of Informed Consent in Subject Recruitment and Retention,” AFFIRM Annual Meeting (Washington, DC).

2/99 **Hull, SC**, “Special Issues in Genetic Research,” Research Ethics and Integrity Course (306.665), Department of Health Policy and Management, Johns Hopkins School of Public Health (Baltimore, MD).

11/30/98 **Hull SC**, “Genetic Exceptionalism, Privacy, and Public Policy,” Science Studies Reading Group, Department of Science and Technology Studies, Cornell University (Ithaca, NY).

4/28/98 Faden RR and **Hull SC**, “Genetics, Public Policy, and Privacy,” Genetic Soup Seminar, Dept. of Medical Genetics, Johns Hopkins Hospital (Baltimore, MD).

**TEACHING**

1/02-3/02 Co-Instructor—Qualitative Research Methods (315.840 Special Studies and Research) Joint Genetic Counseling Training Program, Johns Hopkins Bloomberg School of Public Health and NHGRI, NIH.

- 9/99-present Lecturer—Joint Genetic Counseling Training Program, Johns Hopkins Bloomberg School of Public Health and NHGRI, NIH. Annual lecture on “The NHGRI Institutional Review Board.” Topical lectures on reproductive decision making, research role conflicts and informed consent.
- 5/00-8/00 Mentor—NHGRI Summer Internship Program, NHGRI, NIH.
- 11/99-2/00 Mentor—NHGRI Office of Science Education and Outreach, NIH.
- 3/98 - 4/98 Grader—*The Physician and Society*, Professors Leon Gordis and Henry Seidel, Johns Hopkins University School of Medicine (Baltimore, MD).
- 9/97 - 11/97 Teaching Assistant—*Introduction to Health Policy and Management*, Professor Donald Steinwachs, Johns Hopkins P/T Graduate Program (Washington, DC).
- 1997; 1999 Teaching Assistant—*Research Ethics and Integrity*, Professor Nancy Kass, Johns Hopkins University School of Public Health.

#### **ACADEMIC AND PROFESSIONAL SERVICE**

- 3/99 - present Administrator and member, Institutional Review Board, NHGRI, NIH.
- 12/97-12/98 Member—Committee on Human Research, Johns Hopkins University School of Public Health.
- 7/96 - 1/97 Member—Committee on Campus Violence, Johns Hopkins University.
- 10/93 - 6/94 Member—Animal Care and Use Committee, Johns Hopkins University School of Public Health.
- 10/90 - 5/93 Member—University Board on Student Conduct, Brandeis University.  
Chairperson 9/91 – 5/92.