

## **National Children's Study Federal Advisory Committee Briefing Book**

### **Tab 1: Table of Contents**

### **Tab 2: Agenda**

### **Tab 3: Welcome and Introductions**

- NCSAC Member Roster
- Biographies
- Amended Charter
- Minutes from Previous NCSAC Meeting (April 27–28, 2005)

### **Tab 4: National Research Council/Institute of Medicine Report**

- Ethical Issues in Housing-Related Health Hazard Research Involving Children, Youth and Families (Committee Task)

### **Tab 5: Role of Behavioral and Psychosocial Factors in the National Children's Study**

- From Neurons to Neighborhoods: The Science of Early Childhood Development (Executive Summary)

### **Tab 6: Ethical Considerations: Informing Participants, Families, and Communities of Information Learned**

- The National Children's Study Plan: Revealing Findings/Informing Participants, Families and Others (excerpt)
- NIH Policy on Reporting Results to Subjects
- A Children's Environmental Exposure Research Study – CHEERS Fact Sheet
- Ethical Issues in Genetic Research: Disclosure and Informed Consent
- Informing Study Participants of Research Results: An Ethical Imperative
- Informing Subjects of Epidemiologic Study Results

### **Tab 7: Genetics**

- Office for Human Research Protections (OHRP): Guidance on Research Involving Coded Private Information or Biological Specimens
- National Bioethics Advisory Commission – Research Involving Human Biological Materials: Ethical Issues and Policy Guidance (excerpt)
- Informed Consent for Population-Based Research Involving Genetics
- Problematic Variation in Local Institutional Review of a Multicenter Genetic Epidemiology Study
- Genetic Research Involving Human Biological Materials: A Need to Tailor Consent Forms
- Informed Consent for Research on Stored Blood and Tissue Samples: A Survey of Institutional Review Board Practices

**Tab 7: Genetics (continued)**

- Untapped Potential: IRB Guidance for the Ethical Research Use of Stored Biological Materials
- Informed Consent for Genetic Research on Stored Tissue Samples
- Expanding the Ethical Analysis of Biobanks
- Ethical and Legal Aspects of Applied Genomic Technologies: Practical Solutions
- Race and Ethnicity in the Genome Era: The Complexity of the Constructs
- Community Involvement in the Ethical Review of Genetic Research: Lessons from American Indian and Alaska Native Populations

**Tab 8: Clinical, Economic, and Regulatory Implications  
of the National Children's Study**

- Battelle Report

