



National Cancer Institute
Office of Biorepositories and Biospecimen Research
National Institutes of Health

The Ethical Use of Pediatric Biospecimens in Research

October 24, 2008
8:30 a.m. – 5:00 p.m.

Neuroscience Conference Center
6001 Executive Boulevard
Rockville, Maryland

WORKSHOP SUMMARY

Workshop Description

This one-day workshop will address the ethical issues involved in the storage and use of pediatric biospecimens in research. Select speakers will present regulatory, ethical, clinical and research perspectives on pediatric biospecimen research. Topics will include whether pediatric research participants should be re-consented for ongoing research involving their biospecimens once they obtain the age of majority. Discussion sessions are designed to gain input from all participants and will address specific workshop goals.

Goals

The primary goals of this meeting are to:

1. Identify general ethical concerns regarding use of pediatric biospecimens in future research and develop policies and protections to mitigate these concerns where possible
2. Determine whether genomic research on pediatric biospecimens requires additional protections for research participants
3. Develop recommendations to address whether re-assent and/or re-consent is necessary when biospecimens are collected from children for inclusion in future versions of the *NCI Best Practices for Biospecimen Resources*
4. Develop policies related to the use of pediatric biospecimens appropriate for a large national biorepository

Participants

Invited participants include ethicists, patient advocates, legal experts, administrators of pediatric biorepositories, clinicians and representatives from the Government, including National Institutes of Health and Office of Human Research Protections officials.

Workshop Organization

- The workshop will begin with an explanation of NCI's interest and goals in developing guidance related to the use of pediatric biospecimens in research
- The remainder of the morning session will be devoted to presentations describing the issues involved in research with pediatric biospecimens and panel sessions to allow interaction among all participants
- The afternoon session will consist almost entirely of discussion sessions designed to produce deliverable products from the workshop.