



## Presidential Commission *for the* Study of Bioethical Issues

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### **Obama's Bioethics Commission to Meet in D.C.**

#### **On agenda: medical countermeasures for children; genomics and privacy**

**Who:** Presidential Commission for the Study of Bioethical Issues

**What:** Public Meeting

**When:** Wednesday, August 1, 9 a.m. – 3:00 p.m.  
Thursday, August 2, 9 a.m. – 4 p.m.

**Where:** Renaissance Washington, DC Downtown Hotel, 999 9th Street NW., Washington, DC 20001

**Topics:** Medical Countermeasures for Children; Genomics and privacy

WASHINGTON, D.C. – The Presidential Commission for the Study of Bioethical Issues will hold its tenth public meeting on August 1-2, 2012.

The Commission will continue its work in the following areas:

#### Genomics and Privacy:

Since January 2011 the Commission has been following the pressing problems raised by the emergence of whole genome sequencing as an addition to clinical care and genetic research. The Commission's genomics project seeks to outline many of the key issues surrounding how to reconcile an individual's need for privacy, consent, and respect with the need for gathering data from many individuals to advance discoveries to benefit the common good.

At this meeting the Commission will hear from speakers on a range of topics related to the privacy of and access to genomic data. For example, Latanya Sweeney, Ph.D. of Harvard University and Sonia Suter, M.S., J.D. of George Washington University will discuss how technology is changing views of genomic privacy; and Ken Chahine, Ph.D., J.D. of Ancestry, DNA and Laura Lyman Rodriguez, Ph.D. of the National Human Genome Research Institute will present on the protection of private and public genomic databases.

There will be substantial Member discussion and deliberation as this is the last meeting before the Commission releases its report with recommendations. The Commission expects to deliver a report on genomics and privacy in fall 2012.

Medical Countermeasures for Children:

At the request of Health and Human Services Secretary Kathleen Sebelius, the Commission is conducting a careful and transparent review of the ethical considerations of conducting clinical trials of medical countermeasures with children. The Commission is examining whether the U.S. government should do research that could cause harm to protect children from high consequence events with a low or unknown likelihood of happening. The Commission's report will include the ethical considerations of conducting a pre- and post-event study of an anthrax vaccine as a component of treatment for children exposed to weaponized anthrax.

The Commission will hear from subject matter experts including: David Resnik, J.D., Ph.D. of the NIH, Neal Halsey, M.D. of the Johns Hopkins School of Medicine, and Ruth Berkelman, M.D. of Emory University on the topic of considering individual risk versus Societal Benefit in assessing pediatric research. In addition, the Commission will hear from Paul B. Thompson, Ph.D. of Michigan State University, Richard Gorman, M.D. from the HHS Office of the Assistant Secretary for Preparedness and Response, and from Thomas A. Moore, M.D., F.A.C.P., Chair of the FDA Anti-Infective Drug Advisory Committee about what scientific, medical, and public health information is needed to facilitate decision-making for pediatric research on medical countermeasures.

This meeting is free and open to the public on a first come, first served basis. The Commission will do its best to accommodate requests to speak. Written comments will be accepted and are especially welcome.

The meeting agenda is available on the Commission website at <http://bioethics.gov/cms/node/682>. The meeting will be live-streamed and archived on the Commission website at <https://www.bioethics.gov>. Transcripts will be posted on the website after the meeting.

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