



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 in children; genomics and privacy

- Who:** Presidential Commission for the Study of Bioethical Issues
- What:** Public Meeting
- When:** May 17, 2012
9:00 a.m. - 5:15 p.m.
- Where:** Embassy Row Hotel
2015 Massachusetts Ave. NW
Washington, DC 20036
- Topics:** Medical Countermeasures for Children
Genomics and privacy

WASHINGTON, D.C. – The Presidential Commission for the Study of Bioethical Issues will hold its ninth public meeting on May 17, 2012. At this meeting in Washington, D.C. the Commission is pleased to welcome Health and Human Services Secretary Kathleen Sebelius, who will address the Commission.

In addition, the Commission will hear from subject matter experts in the following areas:

Medical Countermeasures for Children:

On Jan. 10, Secretary Sebelius asked the Commission for ethical advice on the development of medical countermeasures for children. The Commission is well aware that this issue garnered substantial public interest last fall when another Federal advisory committee recommended pediatric testing of the anthrax vaccine. At its May 17 meeting the Commission will take up this issue for the first time and will begin hearing from subject matter experts including David DeGrazia, Ph.D., of George Washington University who will discuss the special ethical

considerations of conducting research with children; Robert “Skip” Nelson, M.D., Ph.D., the Senior Pediatric Ethicist at the Food and Drug Administration, who will outline the current regulatory framework for pediatric research; and Michael R. Anderson, M.D., of the American Academy of Pediatrics who will discuss the practical challenges posed by research with children.

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. According to recent media reports, it is highly likely that 2012 will be the year that the cost of whole genome sequencing will reach approximately \$1,000. What once cost millions may soon cost less than many standard diagnostic tests today.

At its February meeting the Commission focused its study on the ethical issues raised by the ready availability of large-scale human genome sequence data, with regard to privacy and data access and the balancing of individual and societal interests. At its May 17 meeting the Commission will hear from speakers on a range of topics related to the privacy of and access to genomic data. For example, Madison Powers, J.D., D. Phil, of the Kennedy Institute of Ethics, will present a philosophical view of morally-relevant components of privacy; and Leonard d’Avolio, Ph.D., with the US Department of Veterans Affairs (VA) Boston Healthcare System will look at IT/technical issues that are relevant to integrating genomic data into the VA electronic medical record system. The Commission expects to deliver a report on genomics and privacy in fall 2012.

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 www.bioethics.gov. Transcripts will be posted on the website after the meeting.

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