



Presidential Commission *for the* Study of Bioethical Issues

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*****Media Advisory*****

Bioethics Commission to Meet in February in San Francisco

On agenda: medical countermeasures in children, whole genome sequencing, neuroethics

Who: Presidential Commission for the Study of Bioethical Issues

What: Public Meeting

When: Day one: February 2, 2012 9 a.m. – 5 p.m.

Day two: February 3, 2012 9 a.m. – noon

Where: Millberry Union,
University of California, San Francisco
500 Parnassus Avenue
San Francisco, CA 94143

Topics: Medical Countermeasures for Children, Whole Genome Sequencing, Neuroethics

WASHINGTON, D.C. – The Presidential Commission for the Study of Bioethical Issues will hold a public meeting February 2-3 in San Francisco, CA.

Following its report on Human Subjects Protections, the Commission will focus on three projects: medical countermeasures for children, whole genome sequencing and neuroethics.

Medical Countermeasures for Children:

On Jan. 10, Secretary of Health and Human Services Kathleen Sebelius asked the Commission for ethical advice on the development of medical countermeasures for children. The Commission is well aware that this issue garnered significant public interest last fall when another Federal advisory committee recommended pediatric testing of the anthrax vaccine. The Commission is honored that the Secretary has asked for its advice on this important ethical issue. The Commission is reviewing the request carefully and expects to begin work shortly on a timeline to deliver a report in late 2012.

Whole Genome Sequencing:

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.

This will be welcome news for many, however the ethical questions are mounting. For example, the scale of collected and available genetic data raises the bar on data protection, privacy, consent, and counseling. The increased volume of data also increases the potential for use and abuse for nonmedical reasons.

Within this topic, the Commission is exploring issues that include how information is collected and stored, what constitutes informed consent and a host of intersecting privacy and access issues.

During this meeting the Commission will hear from Retta Beery, the mother of twins whose lives dramatically changed for the better after an improved diagnosis gained by whole genome sequencing.

The Commission expects to deliver a report on whole genome sequencing in Fall 2012.

Neuroethics:

Finally, the Commission has been interested in the challenges posed by advances in neuroscience.

The Commission's bioethical inquiry into this topic will likely focus on advances in neuroimaging and the implications for moral philosophy and for moral and legal responsibility.

During this meeting the Commission will also hear from prominent philosopher John Perry, Ph.D. of Stanford University and University of California, Riverside. Perry co-hosts the radio program "Philosophy Talk" heard worldwide.

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 also be accepted and are especially welcome.

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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