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## Secretary's Advisory Committee on Genetics, Health, and Society

Eighteenth Meeting  
March 12-13, 2009  
Washington, D.C.

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### DRAFT AGENDA

#### **Thursday, March 12, 2009**

- 10:00 a.m. – 10:15 a.m.      Opening Remarks  
Steven Teutsch, M.D., M.P.H.  
SACGHS Chair
- 10:15 a.m. – 11:00 a.m.      Update from Centers for Medicare and Medicaid Services (CMS)  
Barry Straube, Chief Medical Officer for CMS and Director of CMS' Office  
of Clinical Standards & Quality
- 11:00 a.m. – 12:00 p.m.      Updates from SACGHS *Ex Officios*
- 12:00 p.m. – 12:45 p.m.      LUNCH
- 12:45 p.m. – 1:00 p.m.      Public Comments

#### **Session on Consumer-Initiated Use of Genomic Services**

- 1:00 p.m. – 1:05 p.m.      Session Overview and Purpose  
Sylvia Au, M.S., CGC  
SACGHS Member
- 1:05 p.m. – 1:15 p.m.      Outcomes of an NIH-CDC Workshop on Personal Genomics (Dec. 2008)  
William (Greg) Feero, M.D., Ph.D.  
Senior Advisor to the Director for Genomic Medicine  
National Human Genome Research Institute  
National Institutes of Health
- 1:15 p.m. – 1:25 p.m.      Genomic Attitudes and Trends  
Christy White  
Cogent Research, LLC
- 1:25 p.m. – 1:35 p.m.      NIH Website for Consumer-Level Information about DTC Genomic Services  
Larry Thompson  
Chief, Communications Branch  
National Human Genome Research Institute

1:35 p.m. – 1:45 p.m.	Plans for the National Academies DTC Workshop Lyla Hernandez, M.P.H. Senior Program Officer Institute of Medicine, National Academies
1:45 p.m. – 1:55 p.m.	Standards for Analytical Validity and Clinical Validity of Genomic Scans Amy Miller, Ph.D. Public Policy Director Personalized Medicine Coalition
1:55 p.m. – 2:05 p.m.	New York State Laboratory Requirements Relevant to Genomic Services Companies Anne Willey, Ph.D., J.D. Director, Office of Laboratory Policy and Planning Wadsworth Center New York State Department of Health
2:05 – 2:20	Q&A
2:20 p.m. – 3:00 p.m.	Committee Discussion of Issues and Next Steps
2:20 p.m. – 2:35 p.m.	Proposal for Short-Term Action Sylvia Au, M.S., CGC
2:35 p.m. – 3:00 p.m.	Committee Discussion
3:00 p.m. – 3:15 p.m.	BREAK

**Session on Informed Consent, Privacy, and Discrimination Issues Related to Genomic Data Sharing**

3:15 p.m. – 3:20 p.m.	Session Purpose and Overview Kevin FitzGerald, S.J., Ph.D., Ph.D. SACGHS Member
3:20 p.m. – 3:50 p.m.	Institute of Medicine Report: Beyond the HIPAA Privacy Rule Larry Gostin, J.D. Chair, IOM Committee on Health Research and the Privacy of Health Information
3:50 – 3:55	Q&A
3:55 p.m. – 4:15 p.m.	Informed Consent Issues of Concern to the Advisory Committee for Heritable Disorders in Newborns and Children (ACHDNC) R. Rodney Howell, M.D. Chair, ACHDNC
4:15 – 4:20	Q&A

4:20 p.m. – 4:45 p.m. Committee Discussion of Issues and Next Steps for Issues Related to Informed Consent on Genomic Data Sharing

**Session on the Genetics Education and Training Task Force**

4:45 p.m. – 5:00 p.m. Update on Education and Training Task Force Data Gathering  
Barbara Burns McGrath, R.N., Ph.D.  
SACGHS Member

5:00 p.m. – 5:30 p.m. Committee Discussion

5:30 p.m. – 5:35 p.m. Closing Remarks – Dr. Teutsch

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**Friday, March 13, 2009**

8:30 a.m. – 8:45 a.m. Opening Remarks  
Dr. Teutsch

8:45 a.m. – 9:15 a.m. Updates from SACGHS *Ex Officios* (continued)

9:15 a.m. – 9:30 a.m. Public Comments

9:30 a.m. – 9:45 a.m. BREAK

**Roundtable on Genetics and the Future of the Health Care System**

9:45 a.m. – 9:50 a.m. Roundtable Purpose and Overview  
Mara Aspinall, M.B.A.  
SACGHS Member

9:50 a.m. – 10:05 a.m. Overview of Key Issues in Health Care Reform  
Robert Epstein, M.D.  
Chief Medical Officer  
Medco

10:05 – 10:10 Q&A

10:10 a.m. – 10:40 a.m. Public Health Payer Perspective  
  
Barry Straube, M.D.  
Chief Medical Officer  
Office of Clinical Standards & Quality  
Centers for Medicare & Medicaid Services  
  
Bruce Quinn, M.D., Ph.D.  
Senior Health Policy Specialist  
Foley Hoag, LLP

10:40 – 10:45	Q&A
10:45 a.m. – 11:25 a.m.	<p>Perspective of Private Health Insurance Companies</p> <p>Sam Nussbaum, M.D. Executive Vice President Clinical Health Policy and Chief Medical Officer WellPoint, Inc.</p> <p>Joanne Armstrong, M.D., M.P.H. Senior Medical Director Aetna</p>
11:25 – 11:30	Q&A
11:30 a.m. – 11:55 a.m.	<p>Perspective of Employer-Based Health Insurance Plans</p> <p>Michael Critelli, J.D. Retired Executive Chairman Pitney Bowes</p> <p>Richard Luetkemeyer, M.D., Medical Director, Population Health Quality Quest for Health; and Assistant Medical Director, Caterpillar, Inc.</p>
11:55 – Noon	Q&A
Noon – 1:15 p.m.	LUNCH
1:15 p.m. – 2:35 p.m.	Committee Discussion with Roundtable Participants
2:35 p.m. – 2:50 p.m.	Summation of Key Roundtable Issues and Next Steps Mara Aspinall, M.B.A.
2:50 p.m. – 3:00 p.m.	Concluding Remarks – Dr. Teutsch
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