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

Twelfth Meeting  
March 26 - 27, 2007  
Adelphi, MD

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## DRAFT AGENDA

### **Monday, March 26, 2007**

8:00 a.m. – 8:30 a.m.

*Opening Remarks*  
Reed V. Tuckson, M.D.  
SACGHS Chair

#### **Update from the Office of the Secretary**

8:30 a.m. – 9:00 a.m.

*Update on the Secretary's Personalized Health Care Initiative*  
Sheila Walcoff, J.D.  
Counselor for Science and Public Health  
Office of the Secretary

8:50 – 9:00

Q & A

9:00 a.m. – 10:00 a.m.

*Briefing on the Activities of the Office of the National Coordinator for Health Information Technology and the American Health Information Community*

9:00 – 9:20

Robert M. Kolodner, M.D.  
Interim National Coordinator  
Office of the National Coordinator for Health Information Technology

9:20 – 9:40

Jodi G. Daniel, J.D., M.P.H.  
Director  
Office of Policy and Research  
Office of the National Coordinator for Health Information Technology

9:40 – 10:00

Q & A

10:00 a.m. – 10:15 a.m.

BREAK

**Session on Genetic Discrimination**

10:15 a.m. – 11:45 a.m.      *Briefing on the Status of the Genetic Information Nondiscrimination Act*

Craig Burton (by phone)  
Deputy Assistant Secretary for Legislation  
Office of the Assistant Secretary for Legislation

Keith Flanagan (by phone)  
Minority Health Counsel  
Senate Committee on Health, Education, Labor and Pensions

Michelle Adams (by phone)  
Legislative Director  
Office of Rep. Louise Slaughter

Brian Petersen (by phone)  
Deputy Legislative Director  
Office of Rep. Judy Biggert

*Committee Discussion*

**Public Comments**

11:45 a.m. – 12:15 p.m.      *Public Comments*

12:15 p.m. – 1:15 p.m.      LUNCH

**Session on Oversight of Genetic Testing**

1:15 p.m. – 1:30 p.m.      *Framing the Session*  
Dr. Tuckson and  
Andrea Ferreira-Gonzalez, Ph.D., Chair, SACGHS Oversight Task Force

*The Oversight System*

1:30 p.m. - 2:25 p.m.      *Primer on the Oversight of Genetic Testing* (by video conference)  
Wylie Burke, M.D., Ph.D.  
Chair  
Department of Medical History and Ethics  
University of Washington School of Medicine

2:15 – 2:25      Q & A

*The Role of the States*

2:25 p.m. – 2:55 p.m.      *New York State’s Clinical Laboratory Evaluation Program*  
Ann M. Willey, Ph.D., J.D.  
Director of Laboratory Policy and Planning  
Wadsworth Center  
New York State Department of Health

2:45 – 2:55 Q & A  
2:55 p.m. – 3:10 p.m. BREAK

**Session on Oversight of Genetic Testing (continued)**

***The Role of the Private Sector***

3:10 p.m. – 3:40 p.m. *Accreditation of Genetic Testing Laboratories*  
Gail Habegger Vance, M.D., FCAP  
College of American Pathologists

3:30 – 3:40 Q & A

3:40 p.m. – 4:10 p.m. *Clinical Laboratory Standard Setting*  
Carolyn Sue Richards, Ph.D.  
Professor of Molecular & Medical Genetics  
Director of the DNA Diagnostic Laboratory  
Oregon Health and Science University

4:00 – 4:10 Q & A

4:10 p.m. – 4:40 p.m. *Development of Clinical Practice Guidelines (by video conference)*  
Alfred Berg, M.D., M.P.H.  
Professor and Chair  
Department of Family Medicine  
University of Washington

4:30 – 4:40 Q & A

4:40 p.m. – 5:30 p.m. *Committee Discussion*

**Tuesday, March 27, 2007**

8:00 a.m. – 8:10 a.m. *Opening Remarks*  
Dr. Tuckson

**Session on Gene Patents and Licensing Practices**

8:10 a.m. – 8:20 a.m. *Overview of Session*  
Jim Evans, M.D., Ph.D.  
Task Force Chair

8:20 a.m. – 9:00 a.m. *Primer on Intellectual Property*  
Jorge Goldstein, J.D., Ph.D.  
Director  
Sterne, Kessler, Goldstein & Fox

8:50 – 9:00 Q & A

**Session on Gene Patents and Licensing Practices (continued)**

9:00 a.m. – 9:50 a.m. *Primer on Intellectual Property Licenses and Transfer Agreements*

9:00 – 9:20 *Federal Sector Role*  
Claire Driscoll  
Director  
Technology Transfer Office  
National Human Genome Research Institute

9:20 – 9:40 *Private Sector Role*  
Lin Sun-Hoffman, Ph.D., J.D.  
Senior Patent Attorney  
Applied Biosystems – An Applera Corporation Business

9:40 – 9:50 Q & A

9:50 a.m. – 10:05 a.m. BREAK

10:05 a.m. – 10:55 a.m. *Policy Primer on Patents Related to Genetic Testing*  
Robert Cook-Deegan, M.D.  
Director  
Center for Genome Ethics, Law, and Policy  
Institute for Genome Sciences and Policy  
Duke University School of Medicine

10:45 – 10:55 Q & A

10:55 a.m. – 11:35 a.m. *Update on the Status of the SACGHS Study*  
Dr. Evans  
Dr. Cook-Deegan  
Christopher Conover, Ph.D.  
Assistant Research Professor of Public Policy  
Terry Sanford Institute of Public Policy  
Duke University

11:35 a.m. – 12:30 p.m. *Committee Discussion*

**Public Comments**

12:30 p.m. – 12:45 p.m. *Public Comments*

12:45 p.m. – 1:45 p.m. LUNCH

**Proposals for New SACGHS Study Priorities**

1:45 p.m. – 2:15 p.m.

*Economic Consequences of Genomic Innovations*  
Steven M. Teutsch, M.D., M.P.H.  
SACGHS Member

2:15 p.m. – 2:45 p.m.

*Evaluation of Real-World Outcomes of Gene-based Applications*  
Gurvaneeet Randhawa, M.D., M.P.H.  
AHRQ *Ex Officio*

Muin J. Khoury, M.D., Ph.D.  
CDC *Ex Officio*

2:45 p.m. – 3:15 p.m.

*Committee Discussion*

**Next Steps**

3:15 p.m. – 3:45 p.m.

*Next Steps and Concluding Remarks*  
Dr. Tuckson

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