 Secretary’s Advisory Committee on Genetics, Health, and Society  

Twelfth Meeting  
March 26 - 27, 2007  
Adelphi, MD  

F I N A L A G E N D A  

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 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

Brian Petersen (by phone)  
Deputy Legislative Director  
Office of Representative 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.  
Task Force Chair

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*  
Gurvaneet 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*

3:15 p.m. – 3:45 p.m.  
*Next Steps and Concluding Remarks*  
Dr. Tuckson

ADJOURN