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

Twelfth Meeting
March 26 - 27, 2007
Adelphi, MD

FINAL 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 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

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