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

Twenty-third Meeting
October 5-6, 2010
Bethesda, MD

DRAFT AGENDA

Tuesday, October 5, 2010

8:30 a.m. – 8:45 a.m. Opening Remarks
 Steven Teutsch, M.D., M.P.H.
 SACGHS Chair

Food and Drug Administration

8:45 a.m. – 9:15 a.m. Updates from the Food and Drug Administration (FDA)
 Elizabeth Mansfield, Ph.D.
 Office of In Vitro Diagnostic Device Evaluation and Safety
 Center for Devices and Radiological Health, FDA

Public Comment Session

9:15 a.m. – 9:45 a.m. Public Comments

9:45 a.m. – 10:00 a.m. BREAK

Genetics Education and Training

10:00 a.m. – 12:30 p.m. Review of Revised Draft Report on Genetics Education and Training and
 Discussion of Revised Draft Recommendations

10:00 a.m. – 10:30 a.m. Summary of Public Comments on Draft Report and Overview of Revisions
 Barbara Burns McGrath, R.N., Ph.D.
 SACGHS Member

10:30 a.m. – 12:30 p.m. Discussion of Final Draft Recommendations
 Facilitators: Dr. Teutsch and Dr. McGrath

12:30 p.m. – 1:30 p.m. LUNCH

Implications of Affordable Whole-Genome Sequencing

1:30 p.m. – 3:30 p.m. Session on the Implications of Affordable Whole-Genome Sequencing
 (WGS)

- 1:30 p.m. – 1:35 p.m. Overview of Session
Charis Eng, M.D., Ph.D.
Paul Billings, M.D., Ph.D.
SACGHS Members
- 1:35 p.m. – 1:55 p.m. WGS from the Laboratory Perspective
Karl Voelkerding, M.D.
Medical Director, Advanced Technology and Bioinformatics
ARUP Laboratories
- 1:55 p.m. – 2:15 p.m. WGS from the Clinic Perspective
David Dimmock, M.D.
Assistant Professor, Department of Pediatrics
Medical College of Wisconsin
- 2:15 p.m. – 3:30 p.m. Committee Discussion
- 3:30 p.m. – 3:45 p.m. BREAK
- Genetic Information Nondiscrimination Act**
- 3:45 p.m. – 4:30 p.m. Update on the Implementation of the Genetic Information Nondiscrimination Act (GINA) and Public Awareness of GINA
- 3:45 p.m. – 4:10 p.m. Public Awareness of GINA
Juli Murphy-Bollinger, M.S.
Project Manager, Genetics and Public Policy Center
Johns Hopkins University
- 4:10 p.m. – 4:30 p.m. Committee Discussion
- Clinical Utility and Comparative Effectiveness**
- 4:30 p.m. – 5:25 p.m. Update on the Clinical Utility and Comparative Effectiveness Research of Genetic Tests
Marc Williams, M.D.
SACGHS Member
- 5:25 p.m. – 5:30 p.m. Closing Remarks – Dr. Teutsch
- Wednesday, October 6, 2010**
- 8:30 a.m. – 8:40 a.m. Opening Remarks
Dr. Teutsch
SACGHS Chair
- Genomic Data Sharing**
- 8:40 a.m. – 11:45 a.m. Perspectives on Group Risks and Benefits Related to Genomic Data Sharing

- 8:40 a.m. – 8:50 a.m. Overview of Session
Charmaine Royal, Ph.D.
SACGHS Member
- 8:50 a.m. – 9:10 a.m. Perspectives of Indigenous Groups about Participation in Genomic Research and Data Sharing
Rebecca Tsosie, J.D.
Professor of Law, Sandra Day O'Connor College of Law
Executive Director, Indian Legal Program
Arizona State University
- 9:10 a.m. – 9:30 a.m. Perspectives of Ethnic and Racial Groups about Participation in Genomic Research and Data Sharing
Vence L. Bonham, Jr., J.D.
Senior Advisor to the Director, Societal Implications of Genomics
Branch Chief, Education and Community Involvement
National Human Genome Research Institute, National Institutes of Health
- 9:30 a.m. – 9:50 a.m. Perspectives on U.S. Policy Needs for Genomic Research and Data Sharing that Involves Groups
Morris W. Foster, Ph.D.
Professor and Acting Chair, Department of Anthropology
Associate Director, Center for Applied Social Research
University of Oklahoma
- 9:50 a.m. – 10:10 a.m. Canadian Policies that Address the Involvement of Groups in Genomic Research and Data Sharing
Laura Arbour, M.D.
Associate Professor, Department of Medical Genetics
University of British Columbia
Director, Medical Genetics
Vancouver Island Health Authority
- 10:10 a.m. – 10:25 a.m. BREAK
- 10:25 a.m. – 10:45 a.m. Committee Discussion with Speakers
- 10:45 a.m. – 11:45 a.m. Committee Discussion

Public Comment Session

- 11:45 a.m. – 12:15 p.m. Public Comments
- 12:15 p.m. – 1:15 p.m. LUNCH

Concluding Business

- 1:15 p.m. – 3:00 p.m. Discussion of Letter from SACGHS to Secretary Sebelius
Facilitator: Dr. Teutsch

3:00 p.m. – 3:30 p.m. Presentation of Certificates of Appreciation
Francis Collins, M.D., Ph.D.
Director
National Institutes of Health

3:30 p.m. – 3:45 p.m. Concluding Remarks – Dr. Teutsch

ADJOURN