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

Twenty-second Meeting
June 15-16, 2010
Washington, D.C.

DRAFT AGENDA

Tuesday, June 15, 2010

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

Selected Federal Updates

8:45 a.m. – 9:45 a.m. Overview of the Genetic Testing Registry and A New Partnership with FDA
on Translational Research
Kathy Hudson, Ph.D.
Chief of Staff
National Institutes of Health

9:45 a.m. – 10:00 a.m. BREAK

10:00 a.m. – 10:45 a.m. Updates and Developments from the Office of the National Coordinator for
Health Information Technology
David Hunt, M.D.
Chief Medical Officer
Office of Health Information Technology Adoption
Office of the National Coordinator for Health Information Technology

10:45 a.m. – 11:15 a.m. CLIAC Recommendations for Good Laboratory Practices for Biochemical
Genetic Testing and Newborn Screening
Bin Chen, Ph.D.
Health Scientist
Division of Laboratory Systems, National Center for Preparedness, Detection,
and Control of Infectious Diseases
Centers for Disease Control and Prevention

Public Comment Session

11:15 a.m. – 11:45 a.m. Public Comments

11:45 a.m. – 12:45 p.m. LUNCH

Implications of Affordable Whole-Genome Sequencing

- 12:45 p.m. – 5:25 p.m. Exploratory Session on the Implications of Affordable Whole-Genome Sequencing (WGS)
- 12:45 p.m. – 12:50 p.m. Introduction
Paul Billings, M.D., Ph.D. and Charis Eng, M.D., Ph.D.
SACGHS Members
- 12:50 p.m. – 1:20 p.m. Overview of WGS
Dietrich Stephan, Ph.D.
President and Chief Executive Officer
Ignite Institute for Individualized Medicine
- 1:20 p.m. – 1:40 p.m. Quality and Management of WGS Data
Clifford Reid, M.B.A., Ph.D.
President and Chief Executive Officer
Complete Genomics
- 1:40 p.m. – 2:00 p.m. Preparing and Managing WGS Data for the Clinical Setting
Martin Reese, Ph.D.
Co-Founder, President, and Chief Executive Officer
Omicia
- 2:00 p.m. – 2:20 p.m. Approaches to Using WGS Data and Clinical Utility
William G. Feero, M.D., Ph.D.
Director, Maine-Dartmouth Family Medicine Residency Program
Associate Professor, Department of Community and Family Medicine
Dartmouth Medical School
- 2:20 p.m. – 2:40 p.m. Impact of WGS on the Practice of Health Care
Emily Edelman, M.S., CGC
Project Director
National Coalition for Health Professional Education in Genetics
- 2:40 p.m. – 2:55 p.m. BREAK
- 2:55 p.m. – 3:15 p.m. Ethical, Legal, and Social Issues of WGS
Richard Sharp, Ph.D.
Director, Bioethics Research
Cleveland Clinic
- 3:15 p.m. – 3:35 p.m. Economic Value of WGS
Steven Teutsch, M.D., M.P.H.
Chief Science Officer
Los Angeles County Department of Health
- 3:35 p.m. – 4:45 p.m. Committee Discussion with Speakers
- 4:45 p.m. – 5:15 p.m. Committee Discussion of Next Steps

5:15 p.m. – 5:25 p.m. Summation of Session
Dr. Billings and Dr. Eng

5:25 p.m. – 5:30 p.m. Closing Remarks – Dr. Teutsch

Wednesday, June 16, 2010

8:00 a.m. – 8:15 a.m. Opening Remarks
Dr. Teutsch
SACGHS Chair

Food and Drug Administration

8:15 a.m. – 8:45 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

Genomic Data Sharing

8:45 a.m. – 10:00 a.m. Issues and Next Steps Related to Genomic Data Sharing

8:45 a.m. – 9:10 a.m. Findings from the Literature and Stakeholder Consultations
Charmaine Royal, Ph.D.
SACGHS Member

9:10 a.m. – 10:00 a.m. Committee Discussion of Next Steps

10:00 a.m. – 10:15 a.m. BREAK

Public Comment Session

10:15 a.m. – 10:45 a.m. Public Comments

Carrier Screening

10:45 a.m. – 11:45 a.m. Issues and Concerns Related to Carrier Screening

10:45 a.m. – 11:05 a.m. An Option for Addressing Issues Related to Carrier Screening
R. Rodney Howell, M.D.
Chair, Secretary's Advisory Committee on Heritable Diseases in Newborns
and Children (SACHDNC)

Sara Copeland, M.D.
Deputy Branch Chief, Genetic Services Branch
Maternal and Child Health Bureau
Health Resources and Services Administration

11:05 a.m. – 11:45 a.m. Committee Discussion

11:45 a.m. – 12:45 p.m. LUNCH

Retention and Use of Residual Dried Blood Spot Specimens after Newborn Screening

12:45 p.m. – 2:30 p.m. SACHDNC Draft Briefing Paper on the Retention and Use of Residual Dried Blood Spot Specimens

12:45 p.m. – 1:05 p.m. Overview of the SACHDNC Draft Briefing Paper
R. Rodney Howell, M.D.
Chair, SACHDNC

1:05 p.m. – 1:25 p.m. Findings from the Institute of Medicine Workshop on Challenges and Opportunities in Using Newborn Screening Samples for Translational Research
Adam Berger, Ph.D.
Project Director
Board on Health Sciences Policy, Institute of Medicine

1:25 p.m. – 1:45 p.m. SACGHS Comments on ACHDNC Draft Briefing Paper
Janice Bach, M.S.
SACGHS Member

1:45 p.m. – 2:30 p.m. Discussion

2:30 p.m. – 2:45 p.m. Concluding Remarks – Dr. Teutsch

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