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

Sixth Meeting
February 28-March 1, 2005
North Bethesda, MD

A G E N D A

Monday, February 28, 2005

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|-------------------------|---|
| 8:30 a.m. - 8:45 a.m. | Opening Remarks
Reed Tuckson, M.D.
SACGHS Chair |
| 8:45 a.m. - 9:45 a.m. | Update on SACGHS Efforts on Genetic Discrimination
Ms. Masny and Ms. Berry |
| 9:45 a.m. - 10:15 a.m. | National Health Information Initiative
Rex Cowdry, M.D.
Office of the National Health Information Technology Coordinator
Department of Health and Human Services |
| 10:15 a.m. - 10:45 a.m. | Report from the Advisory Committee on Heritable Disorders and
Genetic Diseases in Newborns and Children
R. Rodney Howell, M.D., Chair |
| 10:45 a.m. - 11:00 a.m. | BREAK |
| 11:00 a.m. - 11:15 a.m. | Public Comments |
| 11:15 a.m. - 5:30 p.m. | Coverage and Reimbursement of Genetic Tests and Services |
| 11:15 - 12:30 | <i>Full Committee Discussion of Draft Coverage and Reimbursement
Report</i>
Facilitators: Ms. Berry and Dr. Tuckson |
| 12:30 p.m. - 1:30 p.m. | LUNCH |
| 1:30 - 3:30 | <i>Continued Discussion of Coverage and Reimbursement Report</i> |
| 3:30 p.m. - 3:45 p.m. | BREAK |

3:45 – 5:30

Continued Discussion of Coverage and Reimbursement Report

Report of the Genetic Counseling Services Work Group on Evidence Supporting the Value and Effectiveness of Genetic Counseling Services

Tuesday, March 1, 2005

8:30 a.m. – 2:45 p.m.

Large Population Studies: The Opportunities and Challenges

8:30 – 9:00

Conceptual Basis for Large Population Studies of Human Genetic Variation and Common Disease

David Goldstein, Ph.D.
Wolfson Professor of Genetics
University College London

9:00 – 9:30

Public Health Perspective on Large Population Studies of Human Genetic Variation, the Environment, and Common Disease

Gilbert S. Omenn, M.D., Ph.D.
Professor of Internal Medicine, Human Genetics and Public Health
University of Michigan

9:30 – 10:00

Overview of International and National Large Population Studies

Teri Manolio, M.D., Ph.D.
Director
Epidemiology and Biometry Program
National Heart Lung and Blood Institute

10:00 a.m. – 10:15 a.m.

BREAK

10:15 – 10:45

Ethical, Legal and Social Issues of Large Population Studies

Bartha Knoppers, Ph.D., L.L.B.
Professor of Law
Canada Research Chair in Law and Medicine
University of Montreal

10:45 – 11:15

Dichotomy Between Social Identity and Ancestry in Large Population Studies

Charles N. Rotimi, Ph.D.
Professor, Genetic Epidemiology
Acting Director, National Human Genome Center
Howard University

11:15 – 11:45

The UK Biobank

John Newton, Ph.D.
Chief Executive Officer
UK Biobank

11:45 – 12:25	<p><i>Federal Perspectives on the Need for a Large Population Study</i></p> <p>Ruth Brenner, M.D., M.P.H. National Institute of Child Health and Human Development</p> <p>Stephan D. Fihn M.D., M.P.H. Department of Veterans Affairs</p> <p>Alan Guttmacher, M.D. National Human Genome Research Institute</p> <p>Muin J. Khoury, M.D., Ph.D. Centers for Disease Control and Prevention</p>
12:25 – 1:00	<p><i>Roundtable Discussion with Session Participants</i> Facilitator: Huntington Willard Ph.D., Large Population Studies Task Force Chair</p>
1:00 p.m. – 2:00 p.m.	LUNCH
2:00 – 2:45	<p><i>Committee Discussion and Next Steps</i> Facilitator: Dr. Willard</p>
2:45 p.m. – 3:00 p.m.	Public Comments
3:00 p.m. – 3:30 p.m.	<p>Summary Report from the Conference on Promoting Quality Laboratory Testing for Rare Diseases: Follow-up and Future Activities D. Joseph Boone, Ph.D. Assistant Director for Science, Division of Laboratory Systems Centers for Disease Control and Prevention</p> <p>Stephen C. Groft, Pharm.D. Director NIH Office of Rare Diseases</p>
3:30 p.m. – 3:45 p.m.	Committee Discussion
3:45 p.m. – 4:00 p.m.	<p>Closing Remarks Dr. Tuckson</p> <p>ADJOURN</p>