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

Fifth Meeting
October 18-19, 2004
Bethesda, MD

A G E N D A

Monday, October 18, 2004

- 8:30 a.m. – 8:35 a.m. *Welcome and Presentation of Certificates of Appreciation*
Raynard Kington, M.D., Ph.D.
Deputy Director, National Institutes of Health
- 8:35 a.m. – 8:40 a.m. *Remarks of the New SACGHS Chair*
Reed V. Tuckson, M.D.
SACGHS Chair
- 8:40 a.m. – 9:00 a.m. *The Importance of Family History in Health*
Alan Guttmacher, M.D.
Deputy Director, National Human Genome Research Institute
- 9:00 a.m. – 12:45 p.m. *Perspectives on Genetic Discrimination*
- 9:00 – 9:15 Introduction
 Agnes Masny, R.N., M.P.H., M.S.N.
 Chair, SACGHS Task Force on Genetic Discrimination
- 9:15 – 10:25 Panel One: Perspectives of Members of the Public
- Heidi Williams
 - Phaedra Malatek
 - Rebecca Fisher, M.L.I.S.
 - Tonia Phillips
 - Paula Funk
 - Maria Carolina Hinestrosa
 - Phil Hardt
- 10:25 – 10:35 Follow-up Questions for Panel One
- 10:35 – 10:45 BREAK

10:45 – 11:15	<p>Panel Two: Health Care Provider Perspectives</p> <ul style="list-style-type: none"> • Jeff Shaw, M.S. Oncology Genetics Counselor Penrose Cancer Center • Donald W. Hadley, M.S. Associate Investigator, Social and Behavioral Research Branch National Human Genome Research Institute • Mark Brantly, M.D. Professor of Medicine University of Florida Health Sciences Center
11:15 – 11:25	Follow-up Questions for Panel Two
11:25 – 12:05	<p>Panel Three: Additional Stakeholder Perspectives</p> <ul style="list-style-type: none"> • Kathy Hudson, Ph.D. Director, Genetics and Public Policy Center • Jane Massey Licata, J.D., Ph.D. Partner, Licata & Tyrrell P.C. Adjunct Professor, Rutgers School of Law-Camden • Joanne Armstrong, M.D., M.P.H. Senior Medical Director, Women’s Health, Aetna America’s Health Insurance Plans • Michael P. Aitken Society for Human Resources Management
12:05 – 12:15	Follow-up Questions for Panel Three
12:15 – 1:15	<p>Roundtable Discussion with Three Panels Facilitators: Ms. Masny and Dr. Tuckson</p>
1:15 p.m. – 1:30 p.m. (Working Lunch)	BREAK
1:30 p.m. – 4:30 p.m.	<i>Committee Review and Discussion of SACGHS Revised Draft Report on Coverage and Reimbursement of Genetic Tests and Services</i>
1:30 – 1:45	<p>Report of the Deliberations of the Coverage and Reimbursement Task Force Cynthia Berry, J.D. Chair, Coverage and Reimbursement Task Force</p>
1:45 – 2:15	<p>Evaluation of Genomic Applications in Practice and Prevention: Implementation and Evaluation of a Model Approach Linda Bradley, Ph.D. Geneticist, Office of Genomics and Disease Prevention Centers for Disease Control and Prevention</p>

2:15 – 2:30 BREAK
2:30 – 4:30 Review and Discussion of Revised Draft Report
4:30 p.m. – 5:00 p.m. *Public Comments*

Tuesday, October 19, 2004

8:30 a.m. – 1:00 p.m. *Continued Review and Discussion of SACGHS Revised Draft Report on Coverage and Reimbursement of Genetic Tests and Services*

8:30 – 10:15 Continued Review and Discussion of Revised Draft Report

10:15 – 10:30 BREAK

10:30 – 12:15 Continued Review and Discussion of Revised Draft Report

12:15 – 12:30 BREAK

(Working Lunch)

12:30 – 1:00 Sum-up of Decisions and Plans for Gathering Public Comment

1:00 p.m. – 1:30 p.m. *Public Comments*

1:30 p.m. – 2:00 p.m. *Presentation on the Scope, Charge, and Progress to Date of the National Academy of Sciences' Committee on Intellectual Property Rights in Genomics and Protein-Related Invention*
David Korn, M.D., Member, NAS Committee

2:00 p.m. – 2:45 p.m. *Discussion of Proposed Plans for Addressing SACGHS Priority Issues*

Large Population Studies
Huntington F. Willard, Ph.D.
Member, SACGHS Task Force on Large Population Studies

Pharmacogenomics
Emily Winn-Deen, Ph.D.
Chair, SACGHS Task Force on Pharmacogenomics

2:45 p.m. – 3:15 p.m. *Next Steps and Closing Remarks*
Dr. Tuckson

ADJOURN